Developing a complex intervention to coordinate care for people with dementia

Submitted by Amy Backhouse

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I certify that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

Signature: ……

Amy Eloise Backhouse

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Abstract

The degenerative nature of dementia and its complexity of needs is becoming an increasing challenge to UK health and social care. Current care services have been reported as fragmented, providing poor quality of care and poor value for money. Coordinating interventions have shown a potential to improve outcomes for individuals living with dementia through the use of case managers who take responsibility for the provision of care through planning, facilitating and coordinating care. However, there is substantial variation across models including components, implementation methods and settings. The aim of this thesis was to explore these variations and develop a complex intervention to coordinate care for individuals living with dementia through a series of studies following the Medical Research Councils (MRC) framework.

Two exploratory sequential systematic reviews were conducted to evaluate the evidence base for coordinating interventions in dementia. Firstly, thematic synthesis was conducted on data from seven papers from five independent studies evaluating qualitative evidence on the experience and perspectives of stakeholders and their views on key components of coordinating interventions. Synthesis identified five descriptive themes grouped from 32 codes: (1) Case Manager, (2) Communication, (3) Intervention, (4) Resources and (5) Support. The findings demonstrated stakeholders valued coordinating interventions in dementia care, and had clear preferences on the components, implementation methods and settings of interventions. The following systematic review synthesised evidence from 14 identified randomised controlled trials (RCTs) to evaluate the effectiveness of coordinating interventions and investigate associations between identified key components and intervention effects. Meta-analyses found individuals in coordinating interventions showed a significant improvement in caregiver burden and patient behaviour compared to individuals in usual care. Subgroup analyses found coordinating interventions using a case manager with a nursing background showed a greater positive effect on caregiver quality of life than those using case managers from other professions. Interventions that did not provide case managers with

supervision showed a greater effectiveness of reducing rates of institutionalisation than interventions providing supervision.

Evidence from the two systematic reviews were used to inform the development of a conceptual model of a coordinating intervention for dementia care. The conceptual model outlines the resources required for the intervention, intervention components including the activities and outputs required for each component, and the primary, intermediate and long-term outcomes of the interventions at a service user level and a system level. Following the modelling stage, a qualitative study was conducted using semi-structured interviews with 22 stakeholders including individuals with dementia, informal caregivers and a range of professionals from health care, social care and third sector organisation. Interviews were used to explore the perspectives and experiences of a range of stakeholders on the coordination of current services, and their views on the likely acceptability, utility and success of the conceptual model of care.

Thematic analysis identified four overarching themes relating to stakeholder perspectives and experience of current care: (1) Societal Attitudes, (2) Care Conflict, (3) Disconnected Systems, and (4) Living Well with Dementia. A further three overarching themes were identified relating to stakeholders views on the conceptual model: (1) Barriers and Facilitators to Model Implementation, (2) Focus of the Intervention and Case Manager Role, and (3) Attributes of Case Manager. Both service users and professionals described a fractured system of care that they felt reflected existing discriminatory attitudes around dementia and the care of older adults. Participants felt a sense of hopelessness when it came to the treatment of dementia and a lack of accountability when it came to continued support. Many participants saw the value of having a case manager and felt the conceptual model for coordinating care could be effective for individuals living with dementia. However, stakeholders also identified potential barriers to implementation, namely funding, potential overlap with current services and roles, and workload of the case manager.

The work in this thesis has identified a range of intervention components, implementation methods and settings of which stakeholders prefer, some of which have been proven to have associations with intervention effects. Incorporating these preferences into a conceptual model of a coordinating intervention in dementia care had a positive response with both service users and professionals who saw the model as a valuable tool in coordinating services, and a process that could fill a current gap in a fragmented care system.

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List of common abbreviations

APA	American Psychiatric Association
CASP	Critical Appraisal Skills Programme
CI	Confidence Intervals
CMHT	Community Mental Health Team
COREQ	Consolidated Criteria for Reporting Qualitative Research
DALY	Disability Adjusted Life Years
DSM	Diagnostic and Statistical Manual of Mental Disorders
EBM	Evidence Based Medicine
GBD	Global Burden of Disease
GCP	Good Clinical Practice
GP	General Practitioner
HTA	Health Technology Assessment
ICD	International Classification of Disease
I^2	I Squared
JDR	Join Dementia Research
MD	Mean Difference
MDT	Multidisciplinary Team
MeSH	Medical Subject Headings
MRC	Medical Research Council
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
NPI	Neuropsychiatric Inventory
NPT	Normalisation Process Theory

OPMH	Older Peoples Mental Health
OR	Odds Ratio
PenCLAHRC	Collaboration for Leadership in Applied Health Research and Care South West Peninsula
PPI	Patient and Public Involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
PTSD	Post-Traumatic Stress Disorder
RCT	Randomised Controlled Trials
SCID	Structured Clinical Interview Schedule
SD	Standard Deviation
SEM	Standard Error of Mean
SMD	Standardised Mean Difference
WHO	World Health Organisation
YLD	Years Lived with Disability
YLL	Years of Life Lost

CHAPTER 1

Introduction

Chapter outline

In this chapter I outline the background and rationale for my thesis. I discuss the following issues in relation to dementia and coordinating interventions:

- Defining dementia and the impact it has at both an individual and societal level
- The issues around care for chronic conditions and the current care available for dementia
- The development of and evidence for models of coordinating interventions
- The evidence for coordinating interventions in dementia care
- How we can move forward to more standardised and effective coordinating interventions in dementia care
- Finally, I give an overview of my thesis, the aim and objectives, and what I present in each of the thesis chapters

Dementia

Defining dementia

The word dementia is derived from the Latin *dementatus*, which means 'without mind' and used to describe an incapacitating illness encompassing cognitive decline. There are some indications that dementia was recognised as early as 600BC, but it was thought to be a natural process of ageing until Cicero's *De Senectute* (44BC) hypothesised ageing is not necessarily accompanied by these significant mental changes [1]. However, it wasn't until the 19th century that the concept of dementia became more specific, with emphasis on its organic origin and irreversible nature. In the early 19th century Jean Etienne Esquirol described dementia as a *"cerebral disease characterised by impairment of sensibility, intelligence and will"*, and presented a list of plausible causes of dementia [2]. It was in the early 20th century that Alois Alzheimer presented a case study of dementia describing symptoms of hallucinations, delusions, aphasia and diminishing cognitive abilities, with a post-mortem examination revealing the now commonly recognised existence of neurofibrillary tangles and senile plaques. In the mid 1960's Alzheimer's disease was accepted as a condition that could be treated medically, which has since seen a significant increase in research [3].

In modern day, dementia is recognised as a highly incapacitating illness that has become increasingly prevalent. The World Health Organisation (WHO) [4] defines dementia in the International Classification of Disease (ICD)-10 as *"…a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairment of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour or motivation"*. The ability to perform daily activities is impaired and capacity for independent living becomes increasingly compromised. When the American Psychiatric Association (APA) updated the Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV (1994) [5] to the DSM-5 (2013) [6], the term dementia was replaced with 'major neurocognitive disorder'. The criteria for major neurocognitive disorder diagnosis do not include memory impairment, and focuses on decline in function from a previous level of performance in a number of cognitive domains which will be different for every individual. The diagnostic criteria from previous additions of the DSM manual (e.g. DSM-IV, DSM-IV-TR) and the WHO ICD-10 criteria have been used to describe the main subtypes of dementia and their symptomatology. Dementia is an umbrella term for several subtypes including neurodegenerative dementias such as Alzheimer's disease, dementia with Lewy bodies and frontotemporal dementia, vascular dementias and secondary dementias such as Creutzfeldt-Jakob disease and Korsakoff's syndrome.

Although there are common cognitive and physical impairments across dementia subtypes, each subtype can be defined by its own symptomatology and pathology. Alzheimer's disease is the most common form of dementia and thought to account for 60% of dementia cases in the over 65 age group [7]. Alzheimer's disease is commonly described as 'pre-senile' when diagnosed in individuals under the age of 65 [8]. However, this distinction is not used often in diagnosis as symptoms present in the same way regardless of age. Alzheimer's shows a classic progressive onset *"that gets worse over time, gradually interfering with more and more cognitive abilities*" [9].

As with many dementias, Alzheimer's disease affects individuals in different ways, at different times, but there are some common features and progressions. The condition often begins with memory loss showing difficulty in learning and recalling information, with impairment in at least one other cognitive domain. Disturbances in social or occupational function become relentlessly progressive in spite of any psychosocial or pharmacological therapy [10]. In time, this can progress to more severe symptoms such as confusion, disorganised thinking, disorientation in time, space and location, and socially inappropriate behaviour. In the final stages of dementia this can deteriorate and result in loss in the ability to communicate [11]. These symptoms are associated with changes in the brain, most commonly the formation of beta-amyloid plaques outside of neurons and neurofibrillary tangles of tau protein that form inside neurons. These changes are thought to contribute to brain cell death and inhibition of the transport of essential nutrients within neurons causing progressive degeneration. The degeneration can be long lasting, with an average life expectancy between three and 20 years following a diagnosis [12].

Other neurodegenerative dementias include dementia with Lewy bodies and frontotemporal dementia. In Lewy Body dementia, there is an abnormal accumulation of alpha-synuclein protein in neurons, and an increased likelihood of showing early signs of sleep disturbance, visual hallucinations and slowness as well as Parkinsonian movement difficulties. Lewy Body dementia has an insidious onset that can be subtle at first and progresses with fluctuations [13]. Frontotemporal dementia also has an insidious onset, but this is usually early, before the age of 65, and often has a rapid progression. However, this dementia affects the frontal and temporal (side) lobes of the brain, which is associated with an early loss of personal awareness leading to self-neglect. Loss of social awareness also occurs, leading to withdrawal and inappropriate behaviour. At the later stages, individuals can develop gait abnormalities along with primitive reflexes originating in the central nervous system such as the Palmer reflex which is an automatic flexing of fingers to grab [14].

Vascular dementia is the second most common type of dementia with an estimated prevalence of around 20% of all dementias [7]. Vascular dementia has a different aetiology from the

neurodegenerative dementias in that it is caused by a reduced blood supply to the brain due to diseased blood vessels. The onset of vascular dementia is often sudden following a stroke or white matter lesions commonly caused by cardiovascular diseases, cerebrovascular diseases or psychiatric disorders, but can also be gradual. The symptoms can mirror those of Alzheimer's but tend to show early problems with organising, planning and decision making, rather than memory loss, and frequent occurrence of physical symptoms such as muscular weakness or paralysis [11]. There are cases where both vascular dementia and Alzheimer's can coexist; these cases are known as mixed dementia. Evidence has suggested that one third of individuals with vascular dementia will also have pathology of Alzheimer's disease [15], which has important implications in the prevention and treatment of dementia.

Dementia burden for individuals diagnosed

The epidemiological literature describes growing numbers of people living with dementia worldwide, but does not give an indication of the global impact of the disease. There are three interrelated levels at which the impact of dementia can be understood; the individual diagnosed, family and friends, and the wider society.

At an individual level, the person diagnosed with dementia will experience physical and mental ill health, reduced life expectancy and an increasingly impaired quality of life. One measure of the burden to the individual living with dementia is the Global Burden of Disease (GBD) which expresses associated disability and mortality. The GBD estimates burden of disease using an indicator of Disability Adjusted Life Years (DALY) which is calculated using the sum of Years Lived with Disability (YLD) and Years of Life Lost (YLL). While YLD is calculated as number of prevalent cases multiplied by the disability weight, and YLL is calculated as number of deaths multiplied by the standard life expectancy at age of death in years. According to Alzheimer's Disease International (2015) [16], between 2000 and 2012 the number of DALYs attributed to dementia increased by 65% globally and by 77% in the UK. The number of YLLs due to dementia increased by 148% in the UK between 2000 and 2012, and doubled from 4.2 million to 8.3 million globally. Finally, the YLD

increased by 40% globally and by 23.2% in the UK between 2000 and 2012. These figures indicate a burden exceeding estimates for cancer and cardiovascular disease in individuals aged 60 and over.

Alongside cognitive deterioration, individuals living with dementia present with behavioural and psychological symptoms such as depression and anxiety, sleep disturbance, aggression and wandering [17] which contribute to the disability experienced. One prospective cohort study using longitudinal data found statistically significantly higher rates of depression in individuals with mild cognitive impairment and dementia compared to those with normal cognition [18]. Studies estimated that around 25% of dementia patients experience sleep disturbances [19], the aetiology of which are multifaceted. The degradation of neuronal pathways responsible for initiating and maintaining sleep, changes in the hypothalamic suprachiasmatic nucleus and modifications in other brain regions regulating the sleep-wake cycle have been implicated as causal agents in this sleep impairment [20]. Approximately 40% of individuals living with dementia develop the behavioural symptom of aggression [21], which is often treated with antipsychotic medication, itself associated with increased morbidity and mortality [22]. Furthermore, wandering behaviour is often seen in dementia patients, and although its prevalence has been difficult to define, it is associated with more cognitive impairment and experience of sleeping problems [23].

Comorbidity, the presence of one or more additional diseases, is also associated with dementia. A cross-sectional study of 72,815 individuals with a diagnosis of dementia found that those most significantly associated with dementia included, but were not limited to Parkinson's disease, congestive heart failure, cerebrovascular disease, anaemia and chronic skin ulcers [24]. These findings have been supported by other studies of comorbidities in dementia [25, 26]. Usually the reasons for this association between dementia and specific comorbidities are straightforward to infer, and include risk factors (cerebrovascular disease), complications (skin ulcers) or simply age-related comorbidities (osteoporosis) of dementia [24].

People living with dementia and additional physical or mental comorbidities can suffer a more rapid decline in daily functions, an increased risk of early mortality and a reduced quality of

life. One study [27] found dementia patients with comorbidities showed an accelerated decline of one or two years ahead of that for individuals who had dementia but no comorbidities. Sampson et al. (2009) [28] found that dementia patients in the UK were three times more likely to die during their first acute hospital admission than those without dementia, even when controlling for age and severity of acute illness. Furthermore, research has found that individuals diagnosed with dementia and other comorbidities have a greater reduction in their quality of life and functional status than people without dementia [29]. Like the additional behavioural and psychological symptoms associated with dementia, comorbidities are debilitating, problematic and costly, and are contributing factors to dementias' GBD estimates.

Dementia burden for informal caregivers and families

Dementia is often associated with particularly intense care needs, and spouses, family and friends are more likely to be required to provide care and support, with informal caregivers often referred to as *"the invisible patient"*. The experience of caring for someone living with dementia has been described as *"enduring stress and frustration"* [30], with the caregiving experience having strong associations with caregiver burden. Informal care provided by family members, most commonly spouses and children, is estimated to cover 85% of the care needed by individuals with dementia and can amount to costs exceeding $220 billion US dollars [16].

This informal care comes at a price for individual caregivers. Caregiver burden has become a well-recognised phenomenon of dementia care and caregivers are at an increased risk of depression, illness and a decreased quality of life [31]. Furthermore, burden and ill-health of caregivers has been associated with poor outcomes for individuals with dementia, including decreased quality of life and early institutionalisation [32]. As well as poor psychological and physical health outcomes, caregiver burden has been associated with increased utilisation of health services [33, 34] and use of medications [35]. Overall, caregiver burden can amount to significant financial, social and personal costs, and incorporating caregivers in a more holistic approach to care could help address these emotional and financial costs.

Economic and societal impact of dementia

Dementia already imposes significant economic impacts on society through both direct costs (e.g. health and social care) and indirect costs (i.e. unpaid informal caregivers). In 2015, the worldwide costs of dementia were estimated at $817.9 billion US dollars, a rise from $604 billion US dollars estimated in 2010 [16]. Based on current prevalence estimates and accounting for annual inflation, the World Alzheimer Report predicts a global cost of $1 trillion US dollars by 2018 reaching $2 trillion by 2030. A smaller portion of this figure accounts for direct health care costs (19.5%), while the majority relates to direct social care and informal care costs, 40.1% and 40.4% respectively. Alzheimer's Disease International estimated the costs of dementia per person, stratified by GBD, at between $872 US dollars (in South East Asia) and $56,218 US dollars (in North America) per person, per year [16].

A report by the Alzheimer's Society [7] stated the total costs of dementia in the UK were £26.3 billion in 2014, with approximately £32,250 being spent annually per person. This overall cost estimate is 24% higher than the figure reported in 2007. The report estimates the distribution of costs, with £10.3 billion and £11.6 billion being spent on social care and informal caregivers respectively, and £4.3 billion on health care costs. This distribution reflects that in the World Alzheimer's Report [16] on global spending. These economic costs of dementia are showing a general increase which could be due to an increasing number of people living with dementia and/or increasing costs per person because of rising costs of services, development of new services or improvement in access of current services. Prevalence is increasing alongside disease associated costs per person. A combination of both leads to a disproportionate impact of dementia and as such it is a massive global priority.

The enormous economic impact and burden dementia poses has led to the illness being highlighted as a public health challenge on the world stage, which has been reflected in movements on an international level to prioritise dementia. In 2012, WHO and Alzheimer's Disease International [36] made dementia a public health priority and delineated seven action areas; increase national

policies for dementia, increase awareness of dementia, risk reduction and prevention, improve diagnosis rates, support carers, improve information systems and data on dementia, and invest in dementia research and innovation.

This prioritisation of dementia is also present at a national level, and has been echoed by the Government and the National Health Service (NHS). Following the Prime Ministers challenge on Dementia 2015 [37], the Challenge on Dementia 2020 was launched in early 2015 as a national policy paper [38]. Although significant progress has been made in line with the aims set out in the first challenge, the Challenge on Dementia 2020 aims to build on this with a focus on transformation of dementia care, support, awareness and research. The Challenge looks at society at large, including the NHS, social care, voluntary and community sectors and how they respond to the governments' aspirations for care and dementia.

Prevalence and incidence of dementia

Over the last decade in England the total number of people aged 65 or over has increased by 21% and those aged 85 or over the population has increased by 32% [39]. As a consequence of this rapidly ageing population, the prevalence of age-related conditions such as dementia are rising. It is estimated that 850,000 individuals in the UK are currently living with dementia and more than 35 million are affected worldwide. It is estimated that by 2040 81.1 million worldwide will have dementia and the majority of these cases will present in developed countries [40].

Prince et al. (2013) [41] conducted a meta-analysis to estimate the prevalence and numbers of those affected by dementia in 21 GBD regions and found a prevalence of 5%-7% for individuals aged over 60 years in most of the regions investigated. The review also reported variation of prevalence in different regions; a higher prevalence in Latin America of 8.5% in an over 60 population of 52 million and a particularly low prevalence of 2%-4% in sub-Saharan Africa for an over 60 population of 40 million. Following Latin America, Western Europe with an over 60 population of 97 million and North America with an over 60 population of 64 million (studies from the USA only) report the highest prevalence; 6.9% and 6.5% respectively. Rizzi et al. (2014) [42] also found that

Western Europe and North America had the highest prevalence rates of dementia in the over 60 population, with an estimated 4.9 million and 3.4 million respectively living with dementia. However, they were also accompanied by China and the developing Western Pacific which was estimated at 6 million, nearly twice the estimated 3.4 million in North America.

Systematic reviews [41, 42] of dementia prevalence have consistently reported variation across the globe. Many of these reviews have reported a higher prevalence in the Americas and developed Western nations, and lower in less developed regions such as Africa, the Middle East and Eastern Europe. Although this variation in prevalence studies across countries and regions can be linked to methodological differences such as use of different diagnostic tools, or differences in target population such as mean ages, there is potential for more meaningful causation which are discussed below. Countries with high-life expectancies, mainly developed countries, tend to have a higher proportion of oldest old adults (identified as 85 years and above) and a lower proportion of young old adults (65 years and above) [43]. Not addressing these age group differences or adjusting for standardised age in epidemiological studies could also be a source of bias.

In an attempt to explain disparities in dementia prevalence much research has focused on global differences in diet and physical activity. There is evidence that 'Western diets' high in saturated fats such as meat and dairy and simple carbohydrates such as sugars can increase the risk of dementia. These diets have also been associated with causes of vascular dementia such as stroke and cardiovascular disease [44-46]. Observational data suggests the low risk of dementia in some developing countries can also be attributed to diet; diets high in fruits, vegetables and fibre improve well-being and cognitive function, and are associated with a decreased risk of development of pathological processes characteristic of neurodegenerative diseases [47, 48]. Alongside dietary factors, there is substantial evidence that a decrease in the average level of physical activity in Western countries can increase the risk of stroke and cardiovascular disease and potentially contribute to the increased prevalence of dementia [49, 50]. Level of education has also been an

area of interest with research suggesting a higher education level is associated with an increase in cognitive reserve and therefore a lower chance of dementia [51-53].

There are fewer studies on the incidence of dementia than the prevalence. With prevalence measuring the proportion of cases in the population at a given time, incidence conveys the rate of occurrence of new cases. A report by the WHO (2012) [36] estimated 7.7 million new cases of dementia each year worldwide, which suggests one new dementia case every four seconds. The incidence rates are highest in Asia (46%) and lowest in Africa (7%), with Europe and the Americas 31% and 16% respectively. The evidence base for incidence of dementia is dominated by research from Europe and North America, with the overall incidence of dementia in low and middle income countries estimated to be only 10% lower than in high income countries. The incidence of dementia also increases with age, with figures doubling for every 6.3 year increase in age [54].

Dementia care

Care for chronic conditions in an ageing population

Health care providers face a huge challenge when managing the quality of services for chronic conditions. Living with a chronic condition like dementia can increase the complexity of care required and places a different set of demands on health and social care. Chronic conditions are defined by WHO as requiring "*ongoing management over a period of years or decades"* [55] and coordinated efforts from an extensive range of professionals with access to a variety of services and treatments. Chronic conditions are currently the leading cause of poor health in developed countries and are causing over 65% of deaths across the globe [56]. With an ageing population, and for the reasons described above, dementia is quickly becoming one of the most prominent chronic health conditions of the 21st century.

The strongest risk factor for developing dementia is age, with the risk doubling every five years after the age of 65 and an estimated one-in-six individuals over the age of 80 living with dementia [57]. Projections by the United Nations suggest the global population of individuals aged ≥80 will be 379 million by 2050, indicating a potential dementia population of 115.4 million [58].

With these estimates of growth, health care systems worldwide need to prepare now to address the specific health issues of older populations. In particular, dementia care will require a holistic approach to support and enable individuals to live well within the restrictions of progressive cognitive and functional decline.

Current dementia care

Due to the chronic and progressive nature of dementia, many individuals who are diagnosed spend considerable time continuing to live at home before, if at all, moving to an institution. In order to make a clear distinction between individuals living in an institution and those living at home, throughout my thesis I refer to the latter group as those living in the community. By institutions, I am referring to individuals residing in care homes, nursing homes, supported living institutions or residential homes. There is some evidence to suggest that individuals living with dementia in the community have lower levels of cognitive impairment and functional decline than those in institutions [59, 60]. In the presence or absence of an informal caregiver, it is important to ensure that people with dementia are able to access the optimum living conditions to enhance independence for as long as is necessary.

In practice, the majority of dementia care takes place in the community and is primarily informal care given by relatives, meaning much of the costs fall to the families [61]. However, there are a number of key organisations involved in the delivery of dementia care. The general practitioner (GP) ultimately remains responsible for people with dementia regardless of their residence, monitoring progression and providing a gateway to services. The NHS predominantly covers health care and provides acute care in hospital settings, as well as community health services such as community mental health teams, memory assessment clinics and outsourced long-term care from independent services. These NHS primary and secondary care services are free at the point of use. Social care services include finding care home placements, providing domiciliary care and day care centres for individuals with dementia, which are all now means tested [62], and there is an abundance of third sector services available dependent on geographical location.

A report by the Royal School of Psychiatrists suggest that older adults occupy over 60% of hospital beds, and over 30% of older adults in hospital have dementia [63]. Individuals with dementia also have a higher rate of unplanned hospital admissions and generally stay longer in hospital which increases financial pressure on the NHS [64]. The increase in use and pressure on acute services has emphasised the need to improve the provision and availability of care and support in the community (NHS 2016 Five Year) [199]. With these figures in mind, there have been several recommendations that resources and funding needs to be shifted from inappropriate acute services and institutional care to community settings in order to focus on crisis prevention [65].

Based on a working group of community providers the King's Fund (2014) [66] produced a report on recommendations of how to transform community services. The report identifies seven main steps for transforming community services to move care closer to home;

(1) Reduce the complexity of services

(2) Wrap services around primary care

(3) Use professionals from all sectors to build multidisciplinary teams (MDT) for people with complex needs

(4) Use specialists and consulting services to support MDT

(5) Offer services alternatives to hospital stays

(6) Build a supportive infrastructure

(7) Incorporate aspects to harness the power of the wider community

Recent NHS strategy plans have incorporated recommendations and emphasised a move towards improving dementia care that meets individuals' needs and prevents unnecessary hospital admissions [67].

As well as a shift in focus to community based care, there has been concern over the best way to deliver more collaborative and coordinated dementia care. Because of the complexity of dementia and the varying needs of individuals and informal caregivers, the range of services required is broad in scope and intensity. There is evidence to suggest that those living with dementia

and carers find it difficult to navigate a fragmented health and social care system, and struggle to understand when and how to access local services. One study found carers in the UK describe the care system as a maze; *"it's a huge maze, the system, it's a terrible maze"* [68]. A report by the Alzheimer's Society indicates barriers to receiving dementia support are lack of accessible services, lack of cooperation between NHS and social care, lack of a carer to navigate the system and lack of useful information on dementia [69].

Delivering more effective collaborative and integrated services has been a priority for national health and social care for decades [70]. Initiatives and strategies developed and piloted in the last 5-10 years include the development of managed clinical networks [71], integrated care pilots [72] and the integrated care pioneers [73], as well as the inclusion of integration and collaboration in guidelines for dementia health care such as those provided by the National Institute for Health and Care Excellence (NICE) [74]. However, despite shifts in policy and strategy, care services remain fragmented. Dementia care is often targeted and time limited, with a heavy focus on emergency and unplanned care in acute services. The labyrinth of services, practitioners and assessments following a dementia diagnosis still remains confusing for individuals living with dementia and their families [75]. Alongside an uncertain illness trajectory and volatile levels of deterioration, care services in dementia need to make substantial improvements in quality of care, but in particular in collaboration and communication to provide more seamless, coordinated care [76]. There is a varied need for care and for needs to be addressed by different specialities which all relate to one individual and their family, and given the research findings that individuals with dementia and informal caregivers struggle to know when and how to access services, there is a clear need for coordinated care [77]. In the following section I discuss some of care models and their components aimed at coordinating care.

Care coordinating interventions

The chronic care model

Over the past few decades research has given focus to multi-component complex interventions that aim to improve collaboration and coordination of services involved in the care of chronic conditions. This has been reactive in response to the failings of care services to improve in line with standards and guidelines that have been set out. The chronic care model is one of a number of terms including 'chronic disease model' and 'disease management programme' that describes an approach to the management of chronic conditions (see figure 1). The initial development of the model took place in the early 1990's and was created in its current form by Wagner in 1996 [78]. The model originated in the US, and has been used successfully in the management of diseases including diabetes, hypertension and coronary heart disease [79, 80]. The model has more recently been applied to a wider range of conditions including mental health disorders like depression and dementia [81, 82].

The chronic care model emphasises the need for an integrated system and proposes an organising framework incorporating patient, provider and system level factors. The model aims to improve functional and clinical outcomes for patients and carers through productive interactions between informed, activated patients and the prepared, proactive team of health care professionals. The model includes the following health system components that aim to develop collaboration and interactions across health care teams [83]:

- Self-management support
- Delivery system design
- Decision support
- Clinical information systems

Similar models of care, such as collaborative care or case management are also organised around the patient and commonly use one professional who is part of a MDT to coordinate care. This professional is usually based in health or social care, and the terminology in the literature

ranges from generic terms such as case managers [84], care coordinators [85] and care consultants [86] to less commonly used terms such as home care advisors [87] or service coordinators [88]. Throughout my thesis I have referred to the professional in the coordinating role as a case manager as it is the most commonly used term within the health care literature.

Although there has been evidence demonstrating the efficacy of the model, much of this research has focused on limited samples, usually with one specified condition in a particular setting. The organisational culture and its structural features, as well as the individual healthcare provider are just some examples of where variations may affect the implementation of such models [89]. These limitations make it difficult to generalise these findings to other populations. Furthermore, the chronic care model is not a simple solution or quick fix to issues surrounding long-term care for chronic conditions, it is a multidimensional resolution to a very complex problem.

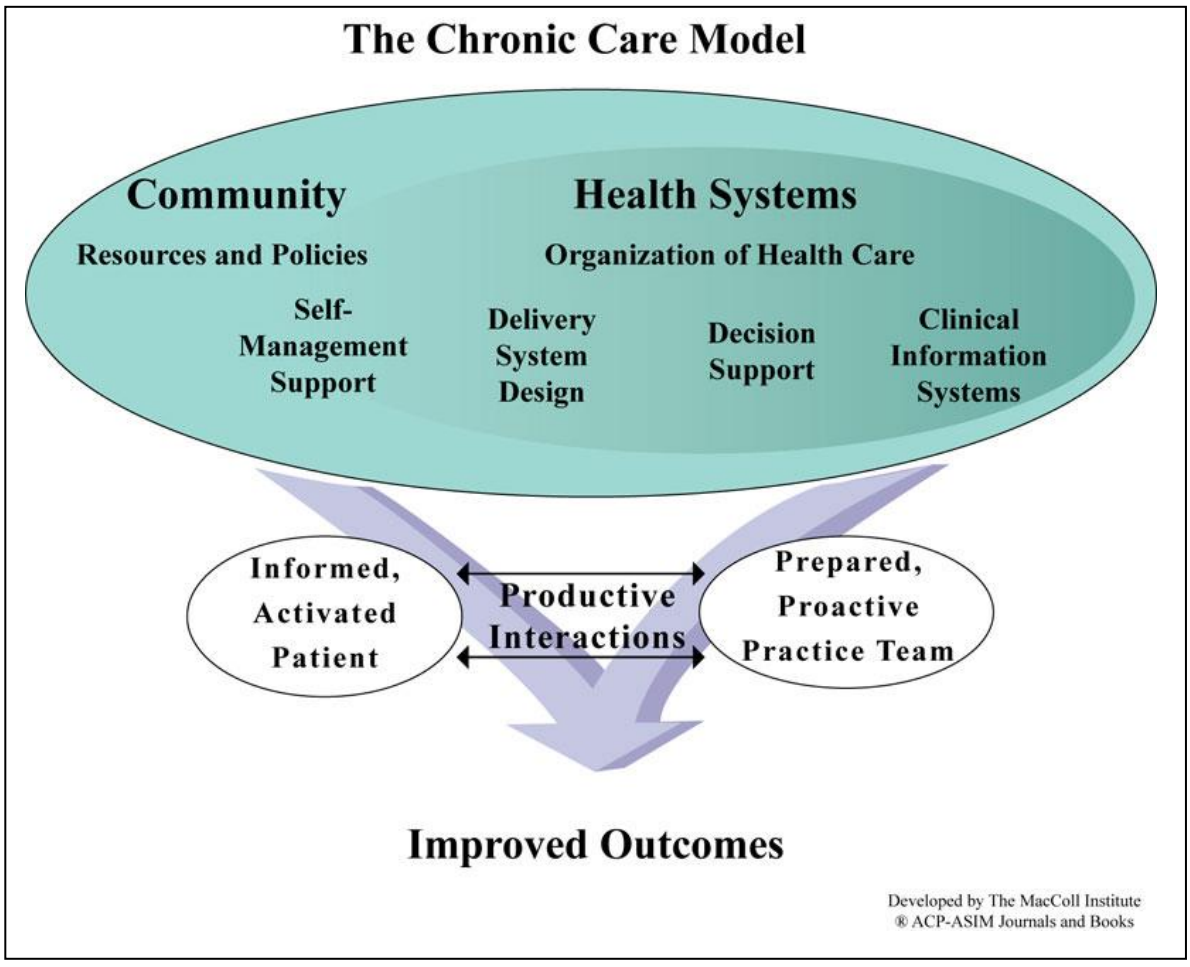

Figure 1: The Chronic Care Model

Collaborative care

Collaborative care has been pioneered by the likes of Von Korff [90] and Wayne Katon [81] who have described this model as *"a systematic approach that helps improve patient education and integrates mental health professionals or other care extenders, such as nurses, into the primary care clinic to help primary care physicians provide treatment in conformity with evidence-based guidelines"* [81]. Collaborative care is similar to the chronic care model, and other coordinating interventions, as it is organised around the patient and with the assignment of one member of a MDT in a coordinating role. Guidelines and protocols are used to delivered evidence-based treatment and case managers are proactive in their follow-ups and medication reviews. Although collaborative care has been given a variety of definitions and structures, a more recent and highly structured definition by Jane Gunn (2006) [91] has become more established. Gunn outlines four components for collaborative care;

(1) A multi-professional approach to care through the use of case managers, GPs and other health care professionals (e.g. nurse, psychiatrists and pharmacists)

(2) A structured management plan in the form of protocols that may include medication management and psychological therapies

(3) Scheduled follow-ups with patients either by telephone or face-to-face to provide intervention, facilitate treatment or care, or monitor symptoms

(4) Enhanced inter-professional communication through MDT meetings, supervision, sharing information and patient feedback.

There is a strong evidence base for the effective use of collaborative care models. Katon and colleagues conducted a series of studies in the United States investigating the effectiveness of collaborative care in various conditions. In early work, Katon et al. (1999) [92] investigated the effects of collaborative care models in depression and found that individuals in the intervention group showed a greater significant decrease in depressive symptoms than those in usual care, and found intervention patients were also more likely to show full recovery at three and six months. In a

later study, Katon et al. (2002) [93] implemented a collaborative care intervention for individuals with panic disorder, with findings showing a significant improvement in the number of anxiety-free days with a mean of 74.2 more anxiety-free days than the control group receiving usual primary care. The intervention focused on improving patient education on medication and integrating a consulting psychiatrist into primary care who was responsible for an initial visit and follow-up phone calls for monitoring. Furthermore, Katon et al. (2004) [94] explored how collaborative care could impact on complex cases involving comorbidities by investigating patients with diabetes and depression. In this study, findings showed a significant improvement in the intervention group compared to the usual care group on a range of outcomes including less depression severity over time, higher rating of patient-rated global improvement and higher satisfaction with care, but showed no difference in diabetes outcomes measured.

This series of studies had a limited sample that was reliant on an accurate diagnosis of the specified condition. The collaborative care models delivered in the studies were in targeted organisations, and therefore did not consider the difficultly in implementing these models in a multifaceted care network. However, Katon and colleagues did demonstrated the potential for collaborative care to have a positive impact for individuals living with a range of chronic conditions in the United States health care system, which was later explored in other populations and health care systems around the world.

In more recent years, research has attempted to implement collaborative care models in UK health care settings. A study by Richards et al. (2013) [95] explored the use of collaborative care in depression in the UK using an intervention delivered by care managers who were supervised by senior mental health specialists, and focused on improving patient education, medication management, brief psychological therapy, relapse prevention and primary care liaison. Findings from this study showed a positive impact on depression scores over a 12 month period. Furthermore, a trial investigating collaborative care in post-traumatic stress disorder (PTSD) and alcohol abuse

found the intervention delivered through trauma centres could effectively lower PTSD symptomatology and decrease the rate of alcohol use/dependence [96].

As with many studies of complex interventions, these trials were left vulnerable to some bias due to difficulty in blinding, for example of clinicians, patients and care managers. Furthermore, Richards et al. (2013) [91] was a cluster randomised controlled trial which can often be prone to selection bias. Like much of the evidence presented in this section, these trials identify a target population of individuals usually with a diagnosis of a specified condition, meaning the findings of trials limited in their generalisability to other conditions and care settings.

A systematic review conducted by Gilbody et al. (2006) [97] explored the effects of collaborative care in depression including 37 randomised controlled trials (RCT) and over 12,000 patients. Findings indicated collaborative care was effective in improving symptoms of depression over 6 months, with some weaker evidence suggesting that these effects were sustained up to five years. This review was updated in 2012 by Thorta et al. [98] who found an additional 32 RCTs, and findings support those of Gilbody et al. [97] in clinically meaningful improvements in depression outcomes. Results from the meta-analysis showed effectiveness of collaborative care in improving depression symptoms, adherence to treatment, treatment response, remission of and recovery from symptoms, quality of life and satisfaction with care. This evidence not only demonstrates that collaborative care models can be effective in improving outcomes for patients, but can also be transferred across different chronic conditions and show a potential to be implemented in different health care settings.

Case management

The general purpose and key functions of case management also reflects other coordinating interventions. Case management appears to be an umbrella-term where implementation may vary on context, professionals involved and target population, and has previously been criticised by Holloway (1991) [99] for being *"used so broadly as to lack any substantive meaning"*. Although disagreement remains on the exact properties and meaning of case management, it is widely

referred to in health care and has some constant functional components including; screening, assessment, planning, linking, monitoring and evaluation [100]. The Case Management Society of America define case management as *"a collaborative process of assessment, planning, facilitation and advocacy for options to meet individuals health needs through communication and available resources to promote quality cost-effective outcomes"* [101]. There is a focus on communication and collaboration at an individual level, an organisational or MDT level of support and involvement of a range of services at a system wide level [102]. These definitions of case management are echoed in both the literature and in national strategy and policy papers recommending the use of case management [103].

Much like other coordinating models of care, case management has been implemented with various different chronic health conditions and across a range of settings. There is a substantial amount of evidence demonstrating the potential for case management to improve clinical outcomes and the processes of care. Evidence for case management has been building for 20 years: a study by Aubert et al. (1998) [104] found using nurse case managers for medication management, diet and exercise education under supervision of an endocrinologist were able to improve glycaemic control in diabetic patients. There is further research to suggest case management can improve the continuity of care [105], overall quality of care [106], professional communication [107] and patient satisfaction with care [108].

Cost-effectiveness of coordinating interventions

The cost-effectiveness of coordinating interventions remains a point of contention within research. A systematic review of collaborative care [109] in major depression analysed eight studies and concluded that the interventions could be cost-effective compared to usual primary care settings. However, another systematic review of collaborative care in depression concluded cost-effectiveness of interventions was somewhat ambiguous and dependent on the willingness to finance interventions [110]. A more recent Cochrane review of case management in dementia [111]

showed potential cost savings in use of services at 12 months follow-ups, and also lower dollar expenditure over the course of three years.

There remains a distinct lack of evidence around the cost-effectiveness of coordinating interventions particularly in UK settings, but given the potential positive effects shown on a range of outcomes, it may be a valuable and meaningful approach to further develop evidence around the care process and improve varied outcomes for those living with chronic conditions. More research is required to address the clinically meaningful outcomes, outcomes that are valued by patients and potential financial savings of coordinating interventions.

Coordinating interventions in dementia care

Evidence in dementia

Many coordinating interventions have been implemented with the older adult population and in particular in dementia care. The field of research around coordinating interventions in dementia care is extensive but evidence of effect is inconsistent. Through scoping the literature I identified a total of six systematic reviews investigating such interventions. Four reviews utilised quantitative research to investigate the effectiveness of coordinating interventions in syntheses focusing on RCTs [111-114]. Two were mixed studies reviews [115, 116] that included studies with a range of designs. All reviews focused on a similar population; individuals who had a diagnosis of dementia or had identified cognitive impairment/ memory loss and were living in the community, and where present the informal caregivers of these individuals. All reviews referred to the intervention as case management where there was a primary focus on the planning and coordinating of care. Further information on the characteristics of the systematic reviews can be found in Table 1.

Two reviews used meta-analytic techniques to synthesise the results of RCTs. Reilly et al. (2015) [111] included 13 RCTs in their meta-analysis and Tam-Tham et al. (2013) [114] included 17, with an overlap of only six studies included on both reviews. Tam-Tham et al. (2013) [114] found that the risk of institutionalisation was significantly reduced in the intervention group prior to 18

month follow-up, but this did not remain significantly reduced after 18 months. However, with the removal of one study with the largest sample and contributing disproportionally to the weight of the analysis, the risk of institutionalisation was significantly reduced after 18 month follow-up. Tam-Tham et al. (2013) [114] found no significant difference between the intervention and usual care groups regarding time to institutionalisation, risk of hospitalisation or number of emergency department visits.

Reilly et al. (2015) [111] found similar results regarding the outcome of care placement. Their findings showed that individuals in the intervention groups were less likely to be institutionalised at 6 month follow-up, at 12 month follow-up where the specified goal of the intervention was to reduce institutionalisation, and again at 18 months. Similarly to Tam-Tham et al.'s [114] findings, this effect was no longer statistically significant by 24 month follow-up. Additionally, Reilly et al. (2015) [111] identified a significant difference in the mean number of days individuals were institutionalised at 6 and 12 months, with individuals in the intervention group being institutionalised for significantly fewer days, but these differences were only reported in one study. Like Tam-Tham et al. (2013) [114], Reilly et al. (2015) [111] found no intervention effect on hospitalisation in number of individuals admitted or in mean number of nights admitted.
Reilly et al.'s (2015) [111] Cochrane review assessed evidence on further patient and caregiver outcome measures. Results demonstrated an initial benefit of coordinating interventions on reducing caregiver burden, but these effects were no longer significant at by 12 months follow-up.

Furthermore, caregiver depression and caregiver well-being showed some significant improvements with coordinating interventions, but the results were not consistent across follow-ups. For patients, there was evidence of coordinating interventions reducing behavioural disturbances, but again these significant findings were not consistent across follow-ups. Reilly et al. (2015) [111] also conducted further analyses on economic data, that indicated coordinating interventions reduced the total cost of services at 12 months and incurred lower dollar expenditure across a sustained three year period.

Both meta-analyses used sound statistical methods to combine evidence increasing the power and accuracy of effect size. Although Tam-Tham et al. (2013) [110] had slightly more trials included, both reviews had a relatively low number of studies and a relatively high number of participants. Each review had one study that dominated the meta-analysis, and although these trials were of high quality the review findings strongly mirror those in the dominant research.

Both Somme et al. (2012) [113] and Pimouguet et al. (2010) [112] conducted narrative syntheses of identified RCTs. Somme et al. (2012) [113] included six RCTs and focused on the primary outcomes of each individual trial, while Pimouguet et al. (2010) [112] included 12 RCTs and focused on synthesising data on health care costs and resource utilisation. Again there was some overlap in the inclusion of RCTs; four of those included in Somme et al. (2012) [113] were also included in the syntheses in Pimouguet et al. (2010) [112], and further overlap with the other reviews.

Somme et al. (2012) [113] importantly highlighted that the included interventions had different end goals, that is, each study aimed to impact a different outcome. In a narrative synthesis Somme et al. (2012) [113] summarised that five of the six included studies had a significant impact on their intended outcome, all of which were different; one study improved adherence to recommended good practice guidelines, another reduced patient behavioural problems, one improved access to services, one significantly offset caregiver depression, whilst another delayed institutionalisation. These findings were presented alongside various other outcome measures, some of which had a significant positive effect in the group who received the coordinating intervention and some of which showed no effect. Pimouguet et al. (2010) [112] also reported inconsistent results, concluding that from the included studies there was no evidence of cost reduction in favour of coordination interventions. However, Pimouguet et al. (2010) [112] did report two good quality RCTs that demonstrated significant improvements in institutionalisation rates, whereas four good quality RCTs did not. The review also reported no significant impact of coordination interventions on hospitalisation rates.

Both Pimouguet et al. (2010) [108] and Somme et al. (2012) [109] provide useful narratives summarising high quality evidence from trials. However, both reviews were much less specific about defining the coordinating interventions than their meta-analytic counterparts, and inclusion criteria that were outlined were much broader. This can present problems with heterogeneity across included studies which would not have been measured and controlled for like it can in a meta-analysis. Pimouguet et al. (2010) [108] also specify the low sample sizes of the included studies give insufficient power to trials, and the short follow-up durations make finding clinically meaningful effect, particularly in the long run, difficult.

Table 1: A summary of systematic review characteristics for coordinating interventions in dementia care

Review ID	*Review type*	*Population*	*Intervention*	*Comparator*	*No. of studies*	*Terminology*
Khanassov 2014a	Mixed studies review	Any age/sex, diagnosis of dementia or cognitive impairment (any type), living in the community, receiving care from health professionals involved in case management	Case management comprising of assessment, care planning, implementation, management and regular follow-up	N/A	23	Case Manager, Case Management
Khanassov 2014b	Mixed studies review	Patients, caregivers, health care professionals involved in case management	Case management interventions comprising all the components by the Case Management Society of America (case finding and screening, assessment, care planning, implementation and management, monitoring and review) for patients any age/sex, diagnosis of dementia or cognitive impairment (any type), living in the community, receiving care from health professionals involved in case management.	N/A	43	Case Manager, Case Management
Pimouguet 2010	Quantitative review, RCTs	Caregiver and/or patients with dementia of any type or memory loss. Any age or sex considered, living in the community	The Case Management Society of America case management definition. Any intervention involving interaction between a case manager and patient-caregiver dyad and providing continuity and advocacy over time, information about community services, care and disease evolution, financial and legal advice. The case manager may also reduce fragmentation among services, monitor medication and give advice on behavioural management strategies	Usual care, or other intervention comparator	12 (13)	Case Manager, Case Management

Reilly 2015	Quantitative review, RCTs	People of any age and gender with dementia of any type, including Alzheimer's disease, vascular dementia or mixed Alzheimer's and vascular dementia, who live in the community (excluding people in institutions) and their carers. Focus on patients only or both patient and carers	Any case management intervention delivered in the community (not in hospital or in residential care settings) that predominantly focused on the planning and coordination of care required to meet the identified needs of the person with dementia	Usual care, non-case management intervention or waiting list controls	13	Case Manager, Case Management
Somme 2012	Quantitative review, RCTs	Patients with Alzheimer's disease and associated disorders (dementia, who were not institutionalised	Case management interventions that include the following tasks; case identification, standardised multidimensional assessment, individualised care plan, implementation of this plan, and monitoring and reassessment of the plan	N/A	6 (17)	Case Manager, Case Management
Tam-Tham 2012	Quantitative review, RCTs	Adults living in the community and diagnosed with dementia and their caregivers	Case management intervention involving at least one health care professional (e.g. nurse or social worker) and providing at least one key component of care (i.e. assessment and planning, education, emotional support, service facilitation, or legal advice and financial counselling) for caregivers and people with dementia	Usual care	17	Case Manager, Case Management

The two remaining systematic reviews were mixed studies reviews. Khanassov et al. (2014a) [116] included a total of 43 studies (31 quantitative and 12 qualitative) and Khanassov et al. (2014b) [115] included 23 (11 quantitative and 12 qualitative). Khanassov et al. (2014a) [116] explored the relationship between key outcomes and barriers to implementation. The quantitative aspect of the review summarised findings from quantitative studies on key outcome measures whilst the qualitative aspect identified barriers to implementation at the level of organisation, clinician and innovation. Interventions that addressed a greater number of barriers showed more positive outcomes, and in a configurational comparative method Khanassov et al. (2014a) [116] reported low-intensity case management and insufficient communication within health care to be the greatest barriers to successful implementation.

Khanassov et al. (2014b) [115] identified factors associated with limiting and facilitating the implementation of coordinating interventions, and then proposed strategies to optimise implementation. The review also uses the Diffusion of Innovation Model [117] as a framework to address the complex conditions inherent in disseminating and sustaining interventions in health care services, and to identify areas with central factors influencing uptake and implementation. Like Khanassov et al. (2014a) [116], the review reported low-intensity case management as a primary limiting factor for implementation, meaning successful implementation was more difficult or less likely using a low-intensity case management. Furthermore, large caseloads and a reactive approach to care were reported as limiting factors. Suggested strategies to address these limiting conditions were the professional development of the case managers through training and education, and the role of the case manager being clearly defined and understood by primary care colleagues.

Both Khanassov papers provide important findings in moving towards deconstructing coordinating interventions that go beyond reviews of effectiveness, and give a good scope of both the qualitative and quantitative evidence available. However, neither review uses statistical analysis with the quantitative evidence, limiting the weight of conclusions and allowing for a range of potential biases and sources of heterogeneity which can be examined in statistical analyses.

Furthermore, the inclusion of both qualitative and quantitative data led to broad inclusion criteria and therefore increased likely heterogeneity across studies. The broad inclusion also meant the analysis conducted lacked any true capacity to draw meaningful links between the two data paradigms.

The majority of reviews concluded that despite the wealth of research there is substantial room for future research in coordinating interventions in dementia care. There were calls for research to focus on the specifics of the case manager, and to concentrate on detailing the content of interventions and core components. For future trials of coordinating interventions, process evaluations were highlighted as vital for helping to identify these components and understand the delivery of interventions, mechanisms by which interventions work and how components relate to outcomes, as well as allow for sustainability and replicability of implementation.

Common features of models

The current systematic reviews on coordinating interventions in dementia care outline a number of inclusion criteria which reflect common features of the interventions. The central role of coordinating interventions is the presence of a named professional, usually a case manager, who is responsible for continued communication between individuals with dementia, informal caregivers and all other professionals and services involved in care [118]. The coordinating role is an important navigational role because of the complexity of dementia needs and variety of input required to meet those needs. Sargent et al. (2007) [119] highlight the importance of coordination that can *"reduce duplication of health care, avoid gaps and reduce health and social care service costs. The benefits to patients are multifaceted and can include improved access to services, avoidance of unnecessary investigations and procedures, improved disease management and faster discharge from hospital"*.

Navigating the complex health and social care system is difficult and confusing when still living at home, and with the extensive availability of services knowing when and how to access these is challenging [68]. With the aim of coordinating a wide range of services and professionals including

primary, secondary and tertiary health care, social care and third sector services, the majority of coordinating interventions are for individuals living in the community.

The case manager often works within a team of multidisciplinary professionals who help to organise and deliver care. The MDT is usually tasked with monitoring and reviewing the caseload of case managers. The different experiences of the MDT members can be used to resolve issues with difficult cases and to discuss the progress of care for individual cases [120]. In addition, individuals living with dementia will require a range of care inputs which can be sourced from the MDT with different skill sets and backgrounds [121].

Once individuals are enrolled in coordinating interventions, one of the first tasks of case managers is to conduct a comprehensive assessment of individuals' current needs. Initial assessments tend to be comprehensive, but can vary depending on the level of risk associated with each patient [122]. The results of assessments are then used to formulate a 'care plan' or 'package of care' that is implemented and managed by case managers. This process aims to join the individual circumstances of each patient with their identified health and social care needs [118]. In the majority of coordinating interventions, the case manager is responsible for care planning in cooperation with individuals living with dementia and caregivers. In some models, this involves a wider co-production with inputs from GPs and other professionals in the MDT [123]. The purpose of the planning process is to provide structure to care, ensuring that the appropriate services are aligned with the identified needs.

The 'care plan' or 'package of care' is seen as a continuing process which is reviewed through scheduled follow-up appointments for monitoring or re-assessment. Follow-up contacts by the case manager are used to ensure that the care in place is meeting the needs of the individual and caregiver, and that progress is being made. Follow-ups are also used to monitor the change in health and social care needs that are inherent in degenerative conditions such as dementia, revising the care plan appropriately [118]. Again, the reviewing of care plans can also incorporate input from various health and social care professionals.

Variation in models

Although there are core features of coordinating interventions, the models implemented in the literature show considerable variation. All six systematic reviews referred to coordinating interventions as case management and the coordinating role as case manager. However, the studies included in each review used a wide variety of terms to refer to each including case management, collaborative care and care consultation, and case manager, care coordinator or in some cases the title of the professional for example GP or geriatric nurse. There is clear evidence on the interchangeability of these terms within literature, and no clear definition of what each intervention or specific role should entail. Throughout my thesis I have chosen to use 'coordinating intervention' as a discrete term to confine the research to the boundaries of a specified model of care.

As well as variation in terminology, there is distinct variation in the components, organisation and implementation of coordinating interventions in dementia care. The case managers themselves have been a source of variation across studies. The case manager role has been occupied by individuals with a range of qualifications, professional backgrounds and skill sets. Professionals such as nurses [124], social workers [125] and occupational therapists [126] have been used, and some trials have used individuals with no clinical or practice qualification [87]. The regularity of contact with individuals with dementia and caregivers also varies across research studies, as well as whether the intervention is strictly telephone based [127]. Although these features are likely to be somewhat dependent on the needs of patients, it could be beneficial to have a standard minimum contact occurrence for research of coordinating interventions.

The target population for coordinating interventions can also differ, this would affect the initial case identification stage. The majority of research is focused on interventions for individuals living with dementia, or on dyads with the inclusion of informal caregivers. However, some research has investigated informal caregivers alone. The Alzheimer's Service Coordination Program [128] used case managers to manage non-medical aspects of care, refer caregivers to community resources, maintain links with primary care physicians, and implement individualised educational and support

plans. Findings showed a significant increase in the self-efficacy of caregivers in managing symptoms of dementia and using community resources, as well as satisfaction in the program from both caregivers and physicians.

With the target population in mind, there is a wealth of outcome measures used to assess the impact coordinating interventions have on a variety of areas in dementia. Health and wellbeing were often the focus of outcomes for individuals living with dementia and included measures of:

- Depression and anxiety
- Cognitive impairment
- Care dependency
- Quality of life
- Memory impairment
- Behavioural problems
- Functional ability
- Unmet needs
- Risk of abuse

Similarly, outcome measures for caregivers centred on health and wellbeing, including measures of:

- Depression and anxiety
- Self-efficacy
- Coping strategies
- Burden
- Relationship strain
- Quality of life
- Support

With case managers being the central role of coordinating interventions, there is also a range of measures related to health care professionals and functional elements including measures of:

- Satisfaction with care
- Knowledge of care
- Attitudes towards dementia
- Perceptions of quality of care
- Service utilisation
- Medication use
- Costs of coordinating interventions

Although the aims of these interventions are to improve the coordination of care, the impact this aims to have on clinical and care process outcomes is inconsistent.

Some models of coordinating interventions use aids such as bespoke information systems or telehealth technology to support implementation. Dang et al. (2008) [129] assisted case managers with installation of a screen phone in participants' house used to set reminders about prescriptions, medication, appointments and other matters. In the UP-TECH project, Chiatti et al. (2013) [130] supported a coordinating intervention through the use of technological house adaptations such as home leaving sensors, automatic lights, gas and water leak sensors and luminous paths. Other studies have used educational tools to support implementation. In a trial by Dias et al. (2008) [87], case managers were responsible for delivering education on dementia, common behavioural problems associated with dementia and how these can be managed. The PREVENT trial incorporated education by providing individuals with dementia and caregivers education on communication skills in dementia [131].

Further differences lie in the use of support groups or incorporation of specific pharmacological elements. In one trial [132] caregivers participated in five goal-oriented peer support group meetings throughout the first follow-up year. Although general medication

management or monitoring is commonly part of coordinating interventions, some studies use qualified case managers to initiate or adjust medication [133]. Furthermore, some coordinating interventions provide individuals with brief psychosocial therapies, such as Chu et al. (2000) [134] where case managers provided counselling sessions for patients.

Moving coordinating interventions forwards

As described above, there is a growing evidence base pointing towards the potential effectiveness of coordinating interventions across a range of health care systems and with a range of chronic and complex conditions including dementia. However, in dementia care this evidence is currently inconsistent. With dementia currently posing one of the largest challenges to health and social care both in the UK and across the globe, coordinating interventions that aim to provide seamless care and facilitate collaboration and communication across services show potential to address these challenges.

Although there are clear similarities across models, coordinating interventions capture a range of complex models of care with clear inconsistencies in the use of terminology and the included components of interventions. These are system level complex interventions comprising of multiple interactive components and involving a wide network of input. The complexity deepens as it becomes difficult to disentangle the components that may be key to successful implementation and those that have the greatest impact on outcomes; the 'active ingredients' [135]. The following section provides an overview of the thesis and how the components of coordinating interventions in dementia care are explored and used to form a conceptual model of care.

Terminology

As discussed in more detail above, I will be referring to professionals in the coordinating role as 'case managers', and to the interventions as 'coordinating interventions'. Furthermore, I have chosen to use the term 'service users' as a collective for the individual with dementia, the informal caregiver(s) and friends and family, for instances where they have shared experiences or opinions. Where evidence has come from a specified group, such as individuals living with dementia

themselves or from informal caregivers, I have stated so. I have used the term 'professionals' when referring to individuals working in health care, social care or third sector organisations. I found these two separate stakeholder groups ('service users' and 'professionals') to be prominent in the literature and have been useful to explore similarities and differences from each group throughout the empirical work of my thesis.

An overview of the thesis

Thesis Aim

To develop a model for a complex intervention to coordinate care for people with dementia.

Thesis objectives

1. To identify key components of coordinating interventions in dementia care for individuals living in the community from the perspectives of varied stakeholders
2. To evaluate the evidence for effectiveness and to identify the extent to which key components contribute to the effectiveness of the intervention
3. To develop a conceptual model of an intervention that coordinates care for individuals living with dementia in the community
4. To investigate current experiences and perspectives of care coordination among service users and professionals, and obtain views on the likely acceptability, utility and feasibility of a conceptual model of care coordination in dementia

Summary of thesis

This thesis consists of seven chapters presenting a consecutive series of studies, each contributing towards the development of a complex intervention coordinating care in dementia. The thesis builds on existing literature outlined in this chapter surrounding coordinating interventions in dementia care that have demonstrated potential to improve outcomes for individuals living with dementia and their informal caregivers. However, it becomes clear that evidence is inconclusive and lacks clarity on intervention models and what components are valued by stakeholders and necessary to generate effect.

In chapter two, I provide the rationale for the studies included in my thesis and the methods used within each study. I also provide a discussion around the more general methodologies and approaches I have used in my thesis including following the Medical Research Councils (MRC) framework for developing and evaluating complex interventions [135], the evidence based medicine movement and the pragmatic approach I have taken to my research.

In chapter three I describe the first study in the thesis; a systematic review of qualitative evidence that explores the experiences and perspectives of a range of stakeholders on coordinating interventions in dementia. Thematic synthesis established a range of components relating to coordinating interventions that stakeholders felt were valued, or elements that were considered as a barrier or facilitator to implementation. In chapter four I then go on to report the findings from a systematic review of quantitative evidence. Meta-analytic techniques are used to pool results of RCTs and evaluate the effectiveness of coordinating interventions in dementia care. Subgroup analyses are conducted to explore heterogeneity of trials and to investigate whether components identified by stakeholders' as valuable were associated with intervention effects.

The results from the reviewing process are then used to inform the development of a conceptual model for a coordinating intervention in dementia care described in chapter five. Where appropriate, components associated with an intervention effect identified in the subgroup analyses were included in the conceptual model, and where components were not appropriate for statistical analyses due to lack of data, I used evidence from the qualitative results in chapter three to inform the development of the intervention. I also use general literature and policy to further inform development.

In chapter six I report a qualitative study using semi-structured interviews with service users and professionals. In this study, I aimed to understand more about current care following a diagnosis of dementia and how it is coordinated, as well as further investigating the need for coordinating interventions in dementia care and developing a deeper understanding of the context in which the

intervention will be situated. I also integrate this information into the intervention development, and explore the views of stakeholders on the conceptual model in light of current UK care settings.

Finally, in the overarching discussion in chapter seven, the rationale, aims, objectives and results of the project are summarised, and the original contributions the thesis makes to the evidence-base and how it fits within existing literature are discussed. I review strengths and limitations across the thesis, and consider the potential implications of the findings for service users, clinicians and the care system, and future research. Based on interpretation of findings and issues discussed, I will draw a final conclusion to the project and answer the overarching questions of my thesis.

CHAPTER 2

An overview of rationale and methodology of the thesis

Chapter outline

In this chapter I discuss the rationale for each study included in my thesis, and discuss the more general methodologies and approaches I have used within the thesis. Presented in this chapter are:

- The rationale for the four empirical chapters of the thesis; a systematic review of qualitative evidence, a systematic review with meta-analyses and subgroup analyses, the development of a conceptual model and a qualitative study
- A discussion around the general methodologies and approaches used in the thesis including following the MRC framework, and using an evidence based medicine and pragmatic approach to research

Rationale for each study in the thesis

Rationale for systematic review of qualitative evidence

After scoping the literature it was clear there was substantial research around coordinating interventions in dementia demonstrating various degrees of effect. However, alongside the inconsistencies in the findings of this research there were considerable inconsistencies in a range of aspects including the target populations, intervention components, intervention delivery and target outcome measures, as well as the terminology describing interventions. Existing systematic reviews of coordinating interventions in dementia have focused on effectiveness, and those incorporating both qualitative and quantitative evidence have drawn no meaningful links between the two strands of data.

More recent reviews [107] have concluded that to move this field forward there is a need to start dissecting coordinating interventions in order to identify what components are working and should be core to future interventions of this kind. In order to address these issues, I designed a systematic review that would incorporate both qualitative and quantitative data, and would attempt to draw meaningful links between both evidence paradigms. Firstly the qualitative evidence would

be addressed in order to identify components stakeholders felt were key to the workings of the interventions, which would be followed by analysing quantitative evidence to investigate if the identified components were associated with intervention effect.

In the field of medicine there has been a movement towards evidence based medicine and systematic reviews have been seen as an accompaniment to such an approach; using evidence to inform clinicians in practice and decision makers in policy [136]. Following the MRC framework [135] for developing complex interventions, which is discussed in detail alongside evidence-based medicine in the following methodological section, the first step of my thesis was to review the evidence for coordinating interventions in dementia care. I addressed this by conducting two sequential systematic reviews incorporating both qualitative and quantitative evidence. Systematic reviews are considered the gold-standard process for reviewing the evidence base with a process that is replicable, scientific and transparent [137], and therefore an appropriate method in reviewing current evidence for coordinating interventions in dementia care.

My initial protocol for reviewing the evidence base was described as a mixed studies systematic review [138]. This is still in keeping, but because of the extent of the reviewing process the entirety of the review is presented in the thesis as two sequential systematic reviews [139] with the results of the first informing the process of the latter.

The first systematic review aimed to explore the experiences, perspectives and views of a range of stakeholders on community-based interventions coordinating care in dementia. As summarised in chapter one, there is synthesised evidence in the form of systematic reviews using meta-analytic or narrative methods that focus on the effects of coordinating interventions, but there is a lack in high-quality syntheses of qualitative evidence. Furthermore, results from previous quantitative syntheses have raised new questions about the structure, organisation and implementation of these interventions. It was therefore important to evaluate the available qualitative evidence with a particular focus on investigating the components that stakeholders felt were important to the workings of coordinating interventions. I identified this as a core question to

underpin the rest of my thesis, and to inform the following subgroup analyses where identified components could be tested as potential associates of intervention effects.

Methods for synthesising qualitative research are relatively new, with the earliest work published in 1988 by Nobit and Hare [140] describing the synthesis of meta-ethnographic evidence, and more recently methods such as meta-synthesis [141], critical interpretive synthesis [142]and meta-study [143] have been developing. Many of these methods are based on the notion of identifying concepts in studies and transferring them, by recognition, between studies.

I chose to use Thomas and Harden's [144] method for thematic synthesis which draws on established methods but primarily adopts the structure of thematic analysis used on primary research to formalise the identification and development of themes. I felt thematic synthesis was the most appropriate method because the purpose of the study was to explore the range of perspectives and experiences of coordinating interventions, and to investigate similarities and differences between themes that were found in available research materials. This method also allowed a degree of flexibility in the level of descriptive and analytic themes.

Rationale for systematic review with meta-analysis and subgroup analysis

Following synthesis of qualitative evidence, I conducted a systematic review using meta-analyses and subgroup analyses of the quantitative evidence available on coordinating interventions in dementia care. RCTs are often considered a high standard of evidence because they allow causal inferences to be drawn. Systematic reviews of RCTs are widely used for evidence synthesis in health services research, usually accompanied by a meta-analysis, which is considered as a standardised process for synthesising RCT evidence and through pooling of results it is possible to produce a more precise estimate of treatment effect [145]. Therefore, for quantitative synthesis I chose to conduct a systematic review to identify relevant trials, and a meta-analysis to evaluate the effect of coordinating interventions on health related outcomes in individuals living with dementia and their informal carers.

I then used the findings from the qualitative synthesis to investigate associations of the identified components with intervention effects on health related outcomes. Although there are existing syntheses of quantitative evidence, none have attempted to draw links with the qualitative evidence base, nor have they sought to dissect interventions to investigate components that may facilitate effect. There are numerous methods available to explore the heterogeneity within meta-analyses but most commonly meta-regression and subgroup analysis. Subgroup analysis was selected because the intervention components from the qualitative synthesis were categorical variables used to define the subgroups; for example grouping trials using a nurse as a case manager and trials using other professionals such as social workers. Meta-regression, although being a more sophisticated approach to explore heterogeneity, is an extension of subgroup analysis for continuous variables and in addition, requires a higher number of trials [146].

Rationale for development of a conceptual model

Results from the syntheses of both qualitative and quantitative evidence were used to inform the development of a conceptual model for an intervention to coordinate care for individuals living with dementia. Where the subgroup analysis had found a component showing a significant association with an intervention effect, then this component was included in the conceptual model. For components that could not undergo statistical analysis, I referred back to qualitative review findings to inform the development of the model and used various literature and policy documents to inform further development.

The modelling process and outcomes is part of the development stage of the MRC framework [135] and is important to produce a standardised intervention protocol. Specific difficulties have been highlighted in the development of complex interventions with inadequate investment at the development stage thought to hinder successful implementation and contribute to research waste [147]. There is a need for clearly defined interventions detailing all aspects from components to outcomes in order to increase transparency and replicability. This stage of the

process is an important step in early intervention development and can be used as an initial framework depicting components and their interrelations.

However, despite the importance placed on this stage of intervention development, there is a lack of detail and guidance on the modelling phase [148]. Therefore I used a combination of literature and existing templates [135, 149] to guide the development process, and followed more specifically the steps of the Centre for Community Health and Developments Community Tool Box framework for development of logic models [150]. In this stage I outline the resources, intervention components and outcomes for the conceptual model.

Rationale for qualitative study

Finally, I conducted a qualitative study using semi-structured interviews to explore the perspectives and experiences of service users and professionals on current services for dementia and how they are coordinated. As the model development had been based on the findings from the systematic reviews, I felt a qualitative study involving a range of relevant stakeholders would be vital to check the reliability and validity of the model. It was also used as a way to inform the contextual detail required for successful implementation, and to develop a relevant intervention for the current UK health care system. Furthermore, I also aimed to investigate the acceptability and utility of the conceptual model, and explore the potential issues with implementation within the current UK health care system. This was important to determine if the intervention meets the needs of service users living with dementia as well as the needs of the professionals delivering dementia care.

Semi-structured interviews were chosen as a qualitative method because it was felt that the one-to-one setup of interviews would provide a safe and encouraging environment for participants to freely express their views in their own time and with their own terms. Using semi-structured interviews supported by a topic guide informed by earlier review results, allowed flexibility in exploring issues relating to the two research questions, and also allowed for open-ended responses from participants to pursue any further lines of inquiry. Other qualitative methods were considered including focus groups. However, it was felt that a group environment may have inhibited honest

and expansive responses to questions. Furthermore, focus groups required a greater organisation and a larger number of participants which was thought to be problematic considering the resource limitations of the PhD project.

In line with the pragmatic approach of the thesis, I chose to take a contextualist approach in the qualitative study. The contextualist approach sits between the dichotomy of realism and constructionism, where the individual makes meaning of their experiences, and in turn the broader social context also imposes on those meanings [127]. The general approaches used in the thesis are discussed later in the chapter, under methodology and approaches.

I chose to use thematic analysis as outlined by Braun and Clarke (2006) [131] to analyse the interview data. Generally, thematic analysis is the most commonly used qualitative approach to analysing interviews and aims to identify, analyse and report patterns in data. The method has been widely and successfully used with qualitative interviews in the field of dementia research, with individuals living with dementia and informal caregivers [151, 152], as well as a range of professionals working in dementia care [153, 154].

I used thematic analysis because it is rigorous in its approach to analysis, it is insightful, and the method allowed a degree of flexibility in addressing the two research questions of the qualitative study. It allowed me to identify the similarities and differences within data sets, which was useful in comparing and contrasting the perspectives of service users and professionals, and allowed for a social as well as psychological interpretation of data [155]. In addition, using thematic analysis complemented the pragmatic approach of the thesis, which I discuss later in this chapter. It facilitated the investigation of interview data from a data-driven perspective based on induction, and then allowed me to relate this to the research questions ensuring data was consistent with the questions and provided sufficient information.

Another consideration when using thematic analysis methods is identifying themes and understanding what counts as a theme, and ensuring there is a consistency in the analysis process of determining themes. Braun and Clarke (2006) [156] define this as a key idea within the data that

relates to the research questions, and that indicates a level of patterned response or meaning within the data. These themes can be identified in an inductive 'bottom up' manner [157] or a deductive 'top down' manner [158]. I have taken the inductive approach to identifying themes, but as previously mention, the pragmatic nature of the thesis allowed for some interaction with influences from existing evidence and most importantly ensuring data was used to answer research questions.

Methodology and approaches

My thesis is structured around the MRC framework [135], a guidance for developing and evaluating complex interventions initially published in 2000[159], but I relied more heavily upon the revised version released in 2008 [135]. The framework outlines the dimensions of complexity involved in many health care interventions and the implications that complexity can have on developing and evaluating interventions. Although very few, if any, health care interventions are truly simple, there is a wide range of complexity that can come from the number of and the interactions between components, the behaviours required, the organisations involved, the variability of outcomes and the flexibility of an intervention. This complexity can affect the development and evaluation of interventions through a lack in understanding the theoretical underpinnings, implementation failures, variabilities at an individual level, wrongly appointed primary outcome(s) or a lack of flexibility.

The MRC framework [135] outlines four main stages of developing and evaluating complex interventions; (1) development, (2) feasibility and piloting, (3) evaluation and (4) implementation (see figure 2). Stage one of the process involves identifying and evaluating the existing evidence base, identifying and developing theory and modelling the process and outcomes. Stage two involves testing the modelled intervention including estimating recruitment and retention numbers, and establishing a sample size needed for a full intervention trial. Stage three involves evaluating the modelled intervention by assessing effectiveness using most appropriate methods, measuring the outcomes and understanding processes of change. This stage can also include an evaluation of cost-effectiveness. The final stage involves implementing interventions into routine practice and policy

through dissemination of findings, observation and monitoring of implementation and long term follow-up.

My thesis is primarily based in stage one of the MRC framework[135] in developing a complex intervention for coordinating care in dementia. Firstly by designing two sequential systematic reviews in chapters three and four that identify and evaluate the current evidence base for coordinating interventions in dementia care, and incorporate evidence from various study methodologies and designs. Modelling the process and outcomes of a complex intervention prior to a full scale evaluation is important to identify potential weaknesses and make refinements for increasing likelihood of successful implementation. Chapter five of my thesis covers this section of the MRC framework in which I have developed a conceptual model of an intervention to coordinate care. As suggested by the MRC framework[135], it can be necessary to supplement existing evidence and theory with primary research such as stakeholder interviews, which has been explored in chapter six of the thesis.

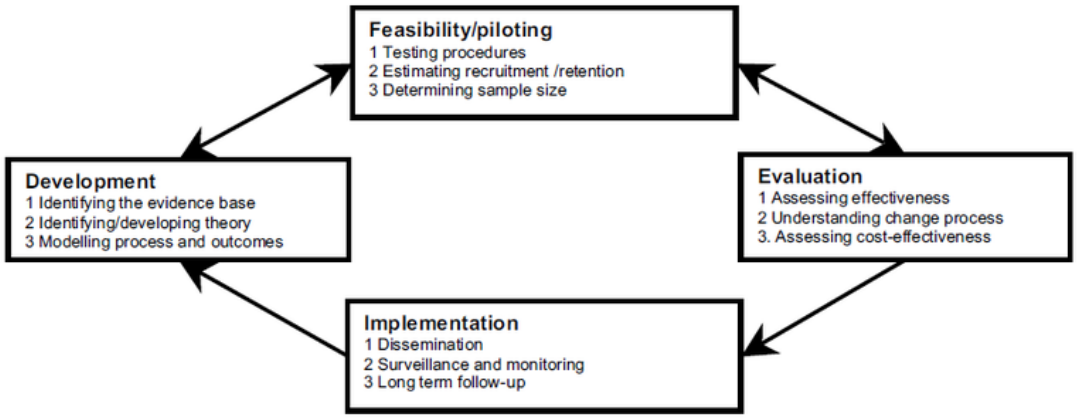

Figure 2: The MRC framework for developing and evaluating complex interventions

The MRC framework[135] focuses on establishing evidence-based interventions that not only include evidence from clinical trials, but incorporates all forms of high-quality evidence. This ethos is aligned with the movement of evidence based medicine (EBM). The EBM movement came as a response to the sheer volume and growth of evidence being produced in health care. It was also

a response to an increased attention to quality standards in clinical research, and aimed to make substantial improvements in the methods and quality of available evidence. In following with the MRC framework[135], my thesis is grounded in EBM.

Although the term EBM and its definition are relatively new, the more general concept has existed for a long time. Claridge and Fabian (2005)[160] describe four main eras of EBM; ancient, renaissance, transitional and modern. Ancient era EBM can be seen as early as the 10th century where teachings were mainly passed on through stories and anecdotal accounts can be seen of elements that reflect modern day EBM. The Renaissance era is thought to begin around the 17th century, where personal journals tended to be kept and the use of textbooks was more popular. Later centuries in the renaissance era began to see some evaluations of the efficacy of treatments such as blood-letting and even amputations. The transitional era of EBM is thought to begin in the late 19th century where knowledge was easily shared and translated in textbooks, and eventually through the use of peer reviewed journals. Finally we find ourselves in the modern era of EBM starting in the late 20th century, where the internet and databases have allowed the gathering of and access to large masses of data and information.

The modern era of EBM has been headed by two prominent figures; Archie Cochrane whose classic text [161] influenced the basis of clinical practice and how we evaluate health interventions, and led to the development of the Cochrane Collaboration that aims to conduct and disseminate up-to-date, accurate systematic reviews of health care interventions. Secondly is David Sackett who defined the term EBM as *"integrating individual clinical expertise with the best available external clinical evidence from systematic research"*[162]. Over the last few decades, in the modern era of EBM, the movement has progressed from traditional and anecdotal basic sciences to a new paradigm of teaching and practising of clinical medicine that aims to incorporate evidence from high-quality research, in combination with clinical expertise and the needs and wishes of patients.

EBM draws on global databases of large-scale health care interventions to generate adequate power to identify important differences between treatments and support the

generalisability of findings[163]. For complex health care interventions such as coordinating interventions, a richer understanding of the context, health care system and intervention characteristics is important in the interpretation of evidence. Following Archie Cochrane's emphasis on amalgamating the best external evidence, and in addressing the above issues, I developed a proposal that reviewed, synthesised and evaluated high quality evidence from both qualitative and quantitative fields of research.

Furthermore, one of the primary reasons for the growing movement of EBM is the gap between research and practice, which reflects a lack of frameworks and strategies that effectively influence clinical practice [164]. Incorporating clinical expertise, in the sense of both the basic skills of clinical practice and the individual experience of practitioners, should help bridge the gap between research and practice. With regards to intervention development, it is important to capture expertise in the early stage of development to enhance the potential for successful implementation in practice.

Service users will have individual preferences for general health care and interventions with varying emotional and social influences. With EBM there has been a move towards capturing and incorporating those views in clinical decision-making and general health care. This comes from a patient-driven argument related to ethical considerations for patient autonomy [165]. In some circumstances, an intervention may be well routed in evidence, but service users will vary widely in their preferences. It is with these issues in mind, and in following with Sackett's [162] emphasis on integrating personal experience, that I designed the qualitative research that aimed to address two arms of evidence based medicine; individual clinical expertise and patient values and expectations.

Alongside EBM and the MRC framework [135], my thesis has taken a pragmatic approach to research where the best evidence was sought using the most appropriate methods for the research questions. This is echoed by its use of the later MRC framework [135] that provides guidance for both experimental and non-experimental methods, and is not solely reliant on RCTs. Much like Sacketts (1997)[162] more recent definition of EBM, pragmatism involves a balance between

research and practice as well as the choice of the individual service user. It is a utilitarian approach that offers an alternative, mixed methodology from the traditional dualism of qualitative and quantitative paradigms, emphasising the ability to link two extremes.

Morgan (2007)[166] outlines a pragmatic approach that offers a more realistic alternative to the three dichotomies of traditional paradigms; inductive vs. deductive, subjectivity vs. objectivity, and context vs. generalisability. Morgan[166] suggests abductive reasoning is an alternate to the purely inductive qualitative approach or purely deductive quantitative approach, and can be applied through moving between data-driven induction and theory-driven deduction. Secondly, Morgan [166] proposes inter-subjectivity as a more realistic approach in practicing research and understanding the relationships between the researcher, other actors and the research process. This is in response to the difficulty in imagining the complete subjectivity of qualitative or the complete objectivity of quantitative approaches. Finally, Morgan[166] hypothesises on the polarisation of context-specific and generalisability of knowledge inferred from data. Pragmatism considers the extent to which we are able to take findings and apply what we learn from one set of individuals in one setting to other circumstances in the most appropriate way.

I incorporated Morgan's [166] three pragmatic alternatives throughout the thesis; abductive reasoning, inter-subjectivity and transferability. An exploratory sequential design was used as abductive reasoning in combining the qualitative synthesis of chapter three and the quantitative synthesis of chapter four, where inductive results served as inputs to deductive goals. An inductive approach was taken to analysing the qualitative data where patterns and regularities in the data were used to form themes directly linked to the data. The findings from this inductive approach were 'mapped' on to identified trials that had used deductive approaches to reach results.

This 'mixing' of qualitative and quantitative approaches in the evidence reviewing stage of intervention design aids the inter-subjectivity by evaluating subjective data from personal experiences of individuals involved in coordinating interventions in dementia care, and objective data from trials. This use of inter-subjectivity addresses the issue of 'no common measure' that has

previously inhibited attempts to form meaningful links between the two strands of qualitative and quantitative data. As researchers we often move between difference frames of reference (e.g. participants, researchers, reviewers and relevant professionals) and the inter-subjectivity in Morgan's pragmatism attempts to find shared meaning across these groups. In this case, the use of both qualitative and quantitative data has sought shared meaning between groups including, but not limited to, individuals with dementia, informal caregivers, case managers, GPs, Psychiatrists and other dementia related professionals.

Forming a conceptual model empirically informed by systematic review results and then seeking validation from professionals and service users' aids in transferability. The reviewing process firstly evaluated context specific qualitative data from a variety of research creating findings limited in their generalisability. The mapping of findings from the qualitative review to the identified trials was key in transferability to the more generalisable findings of the trials. The qualitative study aimed to readdress context within settings relevant to this research, aiming to understand how the current evidence base fits within the context of current UK practice and experience of dementia care.

Doane and Varcoe (2005)[167] argue that a pragmatic approach recognises that knowledge and practice are inseparable, and acknowledges the importance of practice experience in the creation of knowledge. Furthermore, creating knowledge that addresses the complex problems found in clinical practice is vital, and recognising that this can be co-created among researchers, clinicians and service users. Pragmatism is able to embrace the complexities of clinical practice, and aligning this approach with the three pillars of evidence-based medicine; best evidence, clinical experience and patients' values, will offer optimal insights in the early stages of intervention development.

CHAPTER 3

Stakeholders' perspectives on the key components of community-based interventions coordinating care in dementia: a systematic review of qualitative evidence[1]

[1]This chapter is a more detailed version of a published paper. This is in agreement with the Creative Commons Attribution License (CC BY 4.0) that allows authors to share and adapt published intellectual property:

Backhouse A, Richards DA, McCabe R, Watkins R, Dickens C. Stakeholders' perspectives of the key components of community-based interventions coordinating care in dementia: a qualitative systematic review. *BMC Health Services Research*. 2017 doi: 10.1186/s12913-017-2725-y

Abstract

Background: Interventions aiming to coordinate services for the community-based dementia population vary in components, organisation and implementation. This review aims to explore the experiences, views and perceptions of stakeholders on coordinating interventions in dementia care, and investigate their views on the key components of these interventions.

Methods: Four databases were searched from inception to June 2015; MEDLINE (OvidSP), The Cochrane Library, EMBASE and PsycINFO, for qualitative data from qualitative studies, mixed-methods studies and qualitative work embedded within quantitative studies. This search was aided by a search of four grey literature databases, and backward and forward citation tracking of included papers. Title and abstract screening was followed by a full text screen by two independent reviewers, and quality was assessed using the CASP appraisal tool. Thematic synthesis was then used on extracted data.

Results: A total of seven papers from five independent studies were included in the review, and encompassed the views of over 100 participants from three countries. Through thematic synthesis 32 initial codes were identified and then grouped into five descriptive themes: (1) *Case Manager* had four associated codes and described preferences for the case manager personal and professional attributes, including a sound knowledge in dementia and availability of local services; (2) *Communication* had five associated codes and emphasised the importance stakeholders placed on multichannel communication with service users, as well as between multidisciplinary teams and across organisations; (3) *Intervention* had eleven associated codes which focused primarily on the practicalities of implementation such as the contact type and frequency between case managers and service users, and the importance of case manager training and service evaluation; (4) *Resources* had five associated codes which outlined stakeholder views on the required resources for coordinating interventions and potential overlap with existing resources, as well as arising issues when available resources do not meet those required for successful implementation; and (5) *Support* had seven associated codes that reflect the importance that was placed on the support network around the

case manager and the investment of professionals involved directly in care as well as the wider professional network.

Conclusion: The synthesis of relevant qualitative studies has shown how various stakeholder groups considered dementia care coordination interventions to be acceptable, useful and appropriate for dementia care, and have clear preferences for components, organisation and implementation of these interventions. Incorporating stakeholders' perspectives and preferences when planning and developing coordinating interventions may increase the likelihood of successful implementation and patient benefits.

Key words: Dementia, health services, dementia care coordination, case management, systematic review, qualitative research, collaborative care, community interventions

Introduction

Previous systematic reviews, evaluated in chapter one, have been useful in showing the potential for coordinating interventions in dementia care to improve selected health outcomes, but also highlight the uncertain and inconclusive evidence. The reviews have focused on the effectiveness of interventions and have not yet efficiently addressed the qualitative evidence in coordinating interventions in dementia care. Considering the substantial variation of intervention models used in research and practice, as discussed in chapter one, it remains unclear as to how these interventions work and what components are important for improving outcomes.

Understanding the key components of such complex interventions and their effects is likely to be necessary to improve and refine the interventions. In order to address this, I conducted a review of the qualitative evidence to explore the perspectives of stakeholders with respect to active components and mechanisms of effective community-based dementia care coordination interventions, as well as potential ineffective components or barriers to implementation. Reviewing this evidence as an initial step in developing an intervention to coordinate care for individuals living with dementia is in line with stage one of the MRC Framework [135] in identifying the evidence base.

A manuscript of this review has been published in BioMed Central Health Services Research journal [168]. This chapter is a more detailed version of the manuscript submitted. Due to the word limitations of peer-reviewed journals the manuscript was restricted in its detail, in particular the results. I have extended the results section of the review to provide a more comprehensive overview of the qualitative research and a more detailed exploration of the data. Extending the published manuscript has also allowed me to fit the review within the context of the thesis.

Objectives

To synthesise the qualitative literature reporting the perspectives and experiences of stakeholders on community-based interventions coordinating care in dementia, and their views on key components.

Methods

The review protocol was registered with PROSPERO (registration: CRD42015024618), and has been published in BioMed Central Systematic Reviews [138] in accordance with the criteria in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement for systematic reviews[169].

Eligibility criteria

Types of studies: Included studies were those that collected qualitative data on the experiences, perceptions and views of relevant stakeholders on interventions coordinating care in dementia. Study designs consisted of pure qualitative designs, mixed method designs and qualitative work embedded within quantitative studies.

Types of participants: Studies that involved relevant stakeholder groups including individuals with a diagnosis of dementia living in the community and their informal caregivers, case managers, health and social care professionals, and professionals and volunteers from third sector organisations.

Types of intervention: Interventions coordinating care in dementia have been defined for this review as interventions that focused predominantly on planning, facilitating and coordinating care through assessments and proactive follow-ups, delivered by a specified professional in a supporting role for provision and management of care. Studies were included if coordinating interventions were aimed at individuals with a diagnosis of dementia of any type who were living in the community, with no restrictions on age, gender or comorbidities.

Setting: Interventions that were based in the community working with individuals still living at home. Studies were excluded if they were based in hospitals or nursing and residential homes.

Types of outcome measures: Qualitative data relating to the experiences, perceptions and views of relevant stakeholder groups on community-based interventions coordinating care in dementia.

Date, Language and Location: No restrictions were placed on date, language or study location.

Information sources and search strategy

As the initial review protocol outlined a mixed studies systematic review, one search process was conducted covering both qualitative and quantitative evidence (see Appendix 1).

Electronic searches: The following electronic databases were searched from date of inception to June 2015, with the search syntax being modified appropriately for the each database: MEDLINE (OvidSP), The Cochrane Library, EMBASE and PsycINFO. These databases were selected as they are considered preferable databases in medical sciences; they were relevant to the topic under review and were comparable to databases used in identified systematic reviews in a similar field. Furthermore, scoping searches were conducted in a number of relevant databases that further included Web of Science and CINAHL. The four selected produced the most relevant retrievals and with minimal duplication.

Additional resources: A further four electronic databases were searched for grey literature; the Health Management Information Consortium (HMIC), Social Policy and Practice (SPP), ProQuest and the International Clinical Trials Registry Platform (ICTRP). Backward and forward citation searches were also conducted on all included studies, and any relevant systematic reviews identified in the screening process; the reference lists were checked, and relevant titles were included in the screening process.

Search strategy: A comprehensive search strategy was developed through consultation with the PenCLAHRC evidence synthesis team, including terminology identified in scoping the literature and with reference to search strategies of relevant published systematic reviews. The search strategy deployed used a combination of controlled vocabulary specific to the individual database (e.g. MEDLINE Medical Subject Headings (MeSH terms)) and free text terms. The master search strategy deployed in MEDLINE (OvidSP) can be found in Appendix 1.

Study selection

Data management: All references were managed in EndNote X7.0.2. Titles and abstracts of studies identified in the initial search were imported into EndNote, followed by full texts of papers for further screening. Duplicates were removed automatically by EndNote, and assisted by a subsequent hand search.

Screening: Titles and abstracts were screened independently against the inclusion criteria by myself and a colleague (RW). The same reviewers then screened full texts of potentially relevant papers, with any screening disagreements being resolved through discussion or referral to a third reviewer in the supervisory team if necessary.

Data extraction

A bespoke data extraction sheet was used in Microsoft Office Excel software which I piloted on three qualitative papers to extract data on study design, participants and study quality. Nvivo v10 software was then used to extract and manage the findings from the qualitative data. Qualitative data was extracted predominantly from 'results'/'findings' sections of study reports, and additional relevant text under the 'discussion' sections.

Risk of bias

Study quality was assessed using the Critical Appraisal Skills Programme (CASP) qualitative research appraisal tool [170]. CASP was selected because the resource provides tools for each study design and could therefore be consistently used to appraise data for the following systematic review of quantitative evidence. The CASP qualitative checklist includes 10 questions covering rigour, research methods, relevance and research integrity. Quality assessment of all included studies was conducted independently by myself and a colleague (RW), and disagreement was resolved through discussion.

The assessment of quality in qualitative research in systematic reviews has been a long debated issue in evidence synthesis. The methods by which quality should be assessed or whether it should be assessed at all have been questioned, as has the appropriateness of excluding qualitative

studies based on quality [171]. Padgett (1988) [172] warns that using labels *"obscures the blurriness of categories and can easily verge into name calling"*. However, in line with the pragmatic approach of the thesis, the CASP assessment was used to comment on the quality of included studies across the ten questions that are responsive to the unique nature of qualitative inquiry, and was done so as a basis of reducing the risk of arriving at unreliable conclusions.

Data synthesis

The steps outlined by Thomas and Harden (2008) [144] for thematic synthesis of qualitative evidence were broadly followed. The synthesis process began with reading and re-reading the study papers for familiarisation and to develop an initial bank of codes that represented various concepts present within the data. The PDF's of all study papers were imported into Nvivo10 and the text under the 'results'/'findings' sections of each paper underwent line by line coding. In this stage, at least one code was assigned to each line of text, with some lines being assigned multiple codes. This process allows for translation of concepts across studies, and as synthesis progressed the code bank developed through adding, merging and altering codes as they emerged from data. To ensure good saturation of data, the discussion sections of each paper were searched for additional material and relevant data was coded.

For the second stage of thematic synthesis [144] comparisons were drawn across all of the codes, and then codes were grouped based on the similarity of concepts and issues present within each code. This process created a hierarchical structure, with grouped codes forming descriptive themes.

Thomas and Harden [144] describe a third stage in their thematic synthesis that involves the generation of analytic themes. However, they also discuss the relevance of conceptual innovation in this final stage when the primary studies already address the same concepts that are asked in the review questions. In line with the pragmatic approach of the thesis, this final stage was unnecessary for the review and there was no need to go beyond the contents of the original data to yield an appropriate synthesis in answering the review questions.

Results

Study selections

A total of 2718 citations were retrieved and of these seven papers that came from five independent studies were included in the review [84, 88, 173-177]. A full report of the selection process can be seen in the PRISMA diagram in Figure 3.

Three of the papers included in the review were part of a Health Technology Assessment (HTA) feasibility trial called CAREDEM [84, 173, 174]. This meant the three separate papers were reporting on the same data, which was from a nested qualitative study within the feasibility trial. One paper presented the sole findings of the embedded qualitative study and related findings to existing theory [173]; another paper presented a summary of the qualitative findings alongside those of the trial itself [174]; and the final paper was the full HTA report of the trial inclusive of the full qualitative results [84] .

Figure 3: PRISMA diagram for selection process of studies for qualitative synthesis

Study characteristics

Table 2 shows a summary of the five studies included in the qualitative synthesis which were published between 2007 and 2014.

Study participants: One study did not report the sample size [88], and data from the CAREDEM study was reported across three papers [84, 173, 174]. There were over 100 participants across included studies, with one study missing full information on all participants [88] . The studies provide the perspectives of a range of relevant stakeholder groups with extensive experience in dementia care, which included General Practitioners (GPs) (29), carers of individuals with dementia (25), case managers (19), team/ programme managers (9), voluntary sector workers (8+), persons with dementia (6), administrative practice staff (5), project leads and care coordinators of care organisations (5), case manager mentors (4), mental health services representatives (4), municipalities stakeholders (3), commissioners/ funders (2), health insurance company representatives (2), programme coordinators of day care services (2), research team members (2) and old age psychiatrist (1). See Table 2 for full detail of study participants.

Settings: Of the five studies, two were based in the UK [84, 88], two in the Netherlands [176, 177] and one in Canada [175].

Intervention: There were a number of different terms used to describe community-based interventions coordinating care in dementia. The majority of studies referred to the intervention as case management [84, 176, 177]; one study used the term collaborative care [175] and one used dementia support service [88]. All of the interventions had an identified individual responsible for planning, facilitating and/or coordinating care.

Table 2: A summary of characteristics of studies included in the qualitative synthesis

Study ID	*Country*	*Intervention*	*Design*	*Typology*	*Analytic Approach*	*Samples Size*	*Stakeholder Group*
Iliffe 2014a (Bamford 2014; Iliffe 2014b)	UK	Case management	Mixed methods study design	Process evaluation	Framework analysis	49	Person with dementia (6), carer (10), case manager (9), case manager mentor(4), research team members (2), GPs (6), administrative practice staff (5), community mental health team (2), voluntary sector workers (3), commissioners/ funders (2)
Gladman 2007	UK	Dementia support service	Qualitative study design	Service evaluation	Framework analysis	NR	GPs in the locality (6), old age psychiatrist (1), NHS patient advocates (NR), the team manager (1), representatives of the Carer's Federation (NR), representative of Alzheimer's Society (1), carers of service users (15)
Kosteniuk 2014	CANADA	Collaborative Care	Qualitative study design	Exploratory qualitative study	Thematic analysis	15	Family physicians (15)
Minkman 2009	NETHERLANDS	Case management	Qualitative study design	Multiple case study	Thematic analysis	16	Programme managers (8), case managers (8)
Van Mierlo 2014	NETHERLANDS	Case management	Multiple case study design	Process evaluation	Content analysis	22	Case managers (2), project leaders and care coordinators of care organisations (5), GPs (2), health insurance company representatives (2), mental health service representatives (2), programme coordinators of day care service (2), Alzheimer's Netherlands representatives (3), municipalities stakeholders (3), informal caregiver support organisation representative (1)

**NR- not reported*

Risk of bias

A summary of results from the CASP quality appraisal can be found in Table 3, and full results to the ten CASP questions can be found in Appendix 2. All of the included studies had clear research questions, using appropriate methodology and design to address the questions, with all but one study using appropriate recruitment [88]. Data collection was adequately described in all studies, and all had a clear statement of findings. However, in all studies it was unclear as to whether the relationship between the researcher and participant had been adequately considered, question six of the CASP appraisal tool.

The nature and meaning of the relationship between the interviewer and the interviewee has been a topic of debate in qualitative research and understanding whether this is a reciprocal relationship or a relationship with distinct roles is important to consider [178]. The stance on the relationship will influence the approach to interviewing, but this is seemingly under-reported in the literature. Although this has not affected the inclusion of studies or the interpretation of results, it is something that is later considered and discussed with regards to the semi-structured interviews in chapter six.

Table 3: A summary of the CASP quality appraisal for studies included in the qualitative synthesis

Study ID	*Number of questioned answered YES*	*Number of questioned answered CAN'T TELL*	*Number of questioned answered NO*
Iliffe 2014a	8	1	0
Gladman 2007	7	2	0
Kosteniuk 2014	7	2	0
Minkman 2009	6	3	0
Van Mierlo 2014	8	1	0

Results of synthesis

A total of 32 codes were identified and grouped into five descriptive themes which are shown in Table 4. The five descriptive themes were; (1) Case Manager, (2) Communication, (3) Intervention, (4) Resources and (5) Support. These five descriptive themes are discussed in relation to their grouped codes.

Table 4: A table to present the five descriptive themes and 32 codes of the thematic synthesis

Descriptive themes	***Codes***
Case Manager	Case manager interpersonal skills
	Case manager knowledge
	Case manager professional background
	Case manager training
Communication	Case manager role understanding
	Goals and aims
	Multi-disciplinary team
	Multiple organisations
	Research Team
Intervention	Case management contact frequency
	Case management contact type
	Case management tasks
	Case manager base
	Evaluation
	Identifying needs
	Illness trajectory
	Outcome measures
	Proactive
	Therapeutic relationship
	Workload
Resources	Available resources
	Existing roles
	Existing services
	Freeing other resources
	Time constraints
Support	Case management supervision
	Case manager investment
	Continuity of care
	GP investment
	Patient and carer investment
	Primary care team investment
	Value

Case Manager

The case manager theme developed from four of the 32 codes; interpersonal skills, knowledge, professional background and training. Stakeholders across all studies felt the case managers personal attributes were central to the success of the interventions [84, 88, 175-177]. Strong interpersonal skills, such as kindness and empathy [84, 88] were important to service users and thought to help the development of the therapeutic relationship, particularly with sensitive discussions around dementia and care [84]. In one study, professionals emphasized how these skills facilitate effective working with a wide range of individuals from different backgrounds and professions [176].

Knowledge of dementia and knowledge of local services were the two central topics in data around case manager's knowledge and primarily came from professional stakeholders [84, 175-177]. A core understanding of dementia was seen as important for the case managers to enable service users to manage the practicalities and uncertainties of the illness, as well as aiding with signposting duties [84, 176]. Some health care professionals felt case managers knowledge base was more important than their professional background [84, 176], and also suggested an understanding of patient record systems would be useful when working across primary and secondary care [84].

Training was one route to build on knowledge. Many professional stakeholders talked about the importance of providing early, role specific training for case managers' [84, 175]. They referred to inductions to build on existing skills, using assessments to identify educational needs as well as the use of supervision to discuss professional development [84]. Like many components of coordinating interventions, time constraints were considered a barrier to training [84].

All studies included data on the professional background of the case managers', with the most commonly discussed professions being nursing and social work [84, 88, 175-177]. The majority of service users reported no clear preference for case manager professional background. Nurses were seen to be more familiar to service users; they could offer more direct links to the GP and had the potential to address comorbidities. However, some professional stakeholders felt a primary care

based nurse may 'medicalise' the intervention, and may also lack comprehensive knowledge of local community services. Social workers on the other hand were seen as having a good knowledge of community services, and strong links to formal or paid services such as homecare or domiciliary care services. However, professional stakeholders suggested social workers might be more used to working in crisis situations and with larger scale, more complex needs, and therefore may overlook smaller day-to-day needs [84].

Communication

Communication was a strong theme running throughout the data and incorporated five of the 32 codes; role understanding, goals and aims, multi-disciplinary team (MDT), multiple organisations and research team involvement. Professional stakeholders in some studies felt there was confusion over the scope and nature of the case manager role [84, 88, 177], suggesting an initial lack of a clear outline of the intervention led to uncertainties around the boundaries of the role and inconsistent implementation of the intervention. They felt a more precise outline would facilitate investment in the intervention, and improve collaboration and communication across partners [84, 177]. Despite inconsistencies across stakeholder groups in the overarching goals and aims of dementia care coordinating interventions, many were in agreement that it should achieve a holistic and person-centred approach to dementia care that went beyond the measurable outcomes [84, 176]. These goals should be set out in the early stages of intervention development and facilitated through communication across all parties involved [84, 88, 175, 176].

Although the case manager played the central role in the intervention, they were embedded into larger teams who were intended to work collectively as a whole and there would be stages throughout the dementia pathway where different professionals would be involved to varying degrees. Communication in the form of feedback and meetings, alongside shared learning and resources, was seen by some respondents to facilitate a more efficient MDT that could work collaboratively across primary and secondary care [84, 88, 175-177].

As well as having a MDT, it was important coordinating interventions had strong links with third sector organisations. By involving local services, interventions could increase appropriate referrals, share knowledge and expertise, and form a broad dementia care network [84, 88, 175-177]. Professional stakeholders from one study stated this component broadens available information and promotes health and social care integration [177]. One study had substantial data relating to the involvement of the research team in studies of coordinating interventions who were seen as responsible for defining roles and supporting implementation through facilitating communication and collaboration [84]. Furthermore, by having a hands-on research team throughout, investment in the intervention was likely to increase which is vital in the early stages of intervention development and implementation.

Intervention

The intervention theme representing the practicalities of implementation incorporated 11 of the 32 codes; contact frequency, contact type, case manager tasks, case manager base, evaluation, identifying needs, illness trajectory, outcome measures, proactive care, therapeutic relationship and workload. Many stakeholders felt contact type and frequency was dependent on the service users situation [84, 175, 176], a view that follows the person-centred ethos of coordinating interventions. Service users preferred face-to-face contact, and although professionals saw the benefits of this, they highlighted the difficulty of time constraints and suggested telephone contact was a good substitute for maintaining regular contact.

Respondents felt that the initial stages of the intervention should accommodate regular face-to-face contact in order to conduct a comprehensive assessment and develop the therapeutic relationship, and to give professionals a greater understanding of the home environment of service users [84, 88, 176, 177]. Service users saw the therapeutic relationship as a priority in the intervention and described it as a warm and trusting relationship between the case manager, individual living with dementia and the informal caregiver [175]. Stakeholders suggested that if a good therapeutic relationship did not develop, service users were less likely to commit to the

intervention or to make contact with the case manager in times of need. This could hinder the identification of needs and potential benefits of the intervention, as well as increasing likelihood of a crisis situation [84].

Professional stakeholders felt identification of needs should be conducted through regular assessment by a trained case manager. However, this was prohibited by time constraints and the compromised ability of services users to identify their own needs [84, 175]. Some professionals suggested case managers' were often associated with major problems and advice was not sought for lower level, day to day needs [84].Time constraints of case managers' were a common barrier to implementation and dependent on workload which was associated with the case manager caseload [84, 176, 177]. One study suggested the optimum number of cases per case manager should be 50 [176]. In another study, case managers' felt there were unrealistic expectations placed on them; training and continued professional development, implementing care coordination tasks, evaluation and feedback, and conducting research activities [84].

There was a general consensus that dementia care coordinating interventions should be offered at the point of diagnosis [84, 175, 176]. There was some discordance in service user views of appropriate timing; in one study, many individuals who received a case manager at diagnosis felt there wasn't much use for them at that point but they could foresee a point in the future in which it could be utilised. However, several individuals who received a case manager in later stages felt it was provided too late and would have been beneficial at diagnosis [84]. This could be linked to the ability of service users' to identify their own care needs.

Many of these interventions aimed to reduce unplanned hospital admissions and institutionalisation. This was seen by some to be the wrong focus of the interventions considering the inevitably that at some point it will be the most appropriate action for the individual living with dementia. At this point, respondents reported that the case manager should play a role in facilitating the transition to a nursing or care home [84]. Stakeholders also drew attention to the importance of the health and wellbeing of the caregiver, with emphasis on measuring health-related outcomes of

both parties in the dyad [84, 176]. One study also emphasized the importance of both service users and professionals satisfaction with care [176].

A number of tasks were highlighted by professional stakeholders as relevant to the case manager role [84, 88, 175-177]. Many of these were practical activities including; assessments, signposting, referrals, developing and implementing care plans, and maintaining communication across services and partners involved in care. Professionals in one study also highlighted the importance of administrative duties including; recording visits, making field notes and updating patient record systems [84]. Evaluation was important to professionals who felt that there should be evidence of effectiveness and a clear trail of activity. This would allow for implementation issues to be identified early and corrected, and was also seen to facilitate collaboration and support for case managers' [84, 88].

The base of the case manager was a point of contention between varying professional groups [84, 88, 176, 177]. Many professionals felt the GP Practice was an appropriate place for the case manager as it was familiar to service users and could provide direct links to the GP and other clinicians. The practice was also seen to facilitate the uptake and support of dementia care coordinating interventions and could promote team based working [84]. However, other professionals felt the intervention became 'medicalised' in this environment and had increased time pressures in primary care, whereas a community base could allow service users a break from more clinical health settings. Though difficulties were identified in the unfamiliarity of community services and the barriers of integrating with primary care [84].

Resources

Stakeholders across all studies discussed the resources required for successful implementation of coordinating interventions in dementia care, and the consequences when there is a lack in available resources [84, 88, 175-177]. The resources theme encompassed five of the 32 codes; available resources, existing roles, existing services, releasing other resources and time constraints. Time constraint was a common theme in the data, and affected many of the practical

components of the intervention, with case managers' in part-time or dual roles seemed to be reporting the most time pressures [84, 88, 177]. In one study, nurses based in primary care found it difficult to protect time for case manager duties and felt unsupported by colleagues in doing so [84]. In the same study, time pressures were also seen as a barrier to professional development and training opportunities [84].

Most studies presented data around the potential overlap with existing roles and services [84, 175-177]. Admiral Nursing, community mental health nurses and dementia advisors were mentioned as having the potential to duplicate tasks leading to wasted resources. This issue was linked back to the lack of clarity and understanding of the case manager role and coordinating intervention [84, 176]. Professionals outlined aspects such as continuity of care and proactive monitoring of service users as novel and not covered to the same extent by other roles or services, and saw coordinating interventions as plugging a gap in dementia care with a focus on crisis prevention [84]. The collaboration that these interventions encourage across services was also highlighted, and many professionals felt it allowed a greater flexibility of involvement in care [84, 175, 176].

Some professionals stated a failure in coordinating interventions could be attributed to the mismatch in available resources and those required for effective implementation [84]. Ensuring resources were used in the most cost-effective and appropriate manner was important to professionals [84, 175, 176]. In one study professionals discussed finance as a facilitating factor where it was available, but when limited it could create difficulty in expanding coordinating interventions and discourage engagement from stakeholders [177]. One key benefit highlighted was the impact on alleviating pressure on other health resources, specifically GP appointment time. Where the case manager was based in health care, professionals suggested there was some strain lifted from social services particularly with regards to number of referrals being made [84]. Several GPs mentioned they were unable to provide the necessary time to each individual during

consultations, but case managers' were able to give more time to individuals and save GP appointment time [84, 175].

Support

Professionals across all studies talked about the importance of a supporting network around the case manager, and how this can be strengthened through investment by all participating parties [84, 88, 175-177]. The support theme developed from seven of the 32 codes; supervision, case manager investment, continuity of care, GP investment, service user investment, team investment and value.

The investment codes refer to the value that stakeholders placed on the intervention, and the acceptance and willingness to participate. It was important to service users that the case manager showed enthusiasm for the role and acted as an advocate [84], and a lack of investment from the case manager was seen as a barrier to embedding the interventions and engaging other stakeholders. Likewise, professionals emphasised the importance of service users' willingness to participate fully in order to gain the benefits and also to develop a strong therapeutic relationship [84, 177]. The investment of the wider group of professionals, including the GP and the immediate team, was also essential for success. This investment could ease the embedding of the case manager into existing structures and encourage a supportive, collaborative network [84]. The exact role of the GP was vague, with some professionals suggesting GPs should play an intricate role in coordinating interventions and others suggesting a more peripheral role was adequate with updates at regular intervals [84, 177]. Professionals in one study suggested that with a defined role in the intervention the GP may be less likely to have spontaneous requirements and therefore free up appointment time [175].

A number of supportive activities were reported as being in place for the case manager, including supervision or mentoring. The mentor, who was often a senior health care professional, covered tasks including individual case reviews, case manager training and education needs, and encouraging integration of case managers' within relevant teams [84].

Continuity of care was one of the valued components, and providing a single point of contact that offered long-term support was seen to facilitate continuity in the care process [84]. In one study, professionals highlighted that continuity enabled care to develop with the changing needs of service users, which was thought to help improve outcomes including crisis prevention [84]. Service users valued having a single point of contact, and this was seen to facilitate proactive rather than reactive care [84].

Discussion

Summary of evidence

In this review five broad descriptive themes were identified relating to intervention components that stakeholders felt were required for successful implementation from five studies on the experiences and perspectives of stakeholders on coordinating interventions in dementia care. These themes were; (1) Case manager, (2) Communication, (3) Intervention, (4) Resources and (5) Support.

Stakeholders generally considered community-based care coordinating interventions to be acceptable, useful and applicable to dementia care. The 32 codes developed in thematic synthesis not only included practical components such as contact type and frequency, supervision, training and evaluation, but also components that were based around the approach to care including support and investment across stakeholder groups, development of a good therapeutic relationship between case managers' and service users and the value placed on coordinating interventions in dementia care.

There were some differences in the service user and professional stakeholder groups on their views of coordinating interventions. A significant amount of data came from professional stakeholders and seemed to focus on the practical elements of interventions and logistics of coordinating care. There was less data available from service users, but synthesis shows there is more focus on the personal aspects including the character of the case manager and the ability to form a good therapeutic relationship in the right settings.

The findings have shown that stakeholders agree on a set of practical and philosophical underpinnings of community-based coordinating interventions. There is consistency in the preferred personal and professional attributes of case managers', in that they should be warm and empathetic with the ability to develop a strong therapeutic relationship, and have a sound knowledge of dementia and available local services. There is an agreed set of tasks the case manager should complete including assessments, care planning, signposting and referrals, which should be conducted in a proactive manner and an agreement in regular contact that includes face-to-face meetings with service users.

Findings suggest that the case manager should participate in meetings with the immediate MDT as well as meetings with the wider health and social care professional network. However, there is still uncertainty around the details of key individuals or organisations in the wider network and precisely how often contact will need to take place. This is likely to be dependent on the individual case to accommodate the move of health services towards person-centred care. Furthermore, there was a lack in information and detail around the third sector, and who, when and how third sector organisations should be involved in care. Again, this is likely to be dependent on the individual case as well as geographically dependent on local services available.

Synthesis also highlighted some characteristics that may be considered barriers or facilitators in the implementation of a care coordinating interventions. Characteristics highlighted as barriers during implementation included the caseload of the case manager. High caseloads were difficult to manage and were reported to cause reactive care in crisis situations rather than the proactive follow-up care the interventions intended. This was strongly linked to the time constraints of case managers', particularly seen in case managers' working in primary care. Furthermore, a lack in available resources was seen as a barrier to implementation, and referred again to time constraints as well as wider issues like funding.

For facilitating factors, professional stakeholders emphasised the significance of training before beginning the case manager position and also saw the importance of having a supervisor for

guidance and mentoring. Additionally, the embedding of an evaluation element was seen as practical for assessing the effectiveness of the coordinating interventions and as a tool for addressing issues in implementation.

The implementation of coordinating interventions, including the embedding of case managers within existing teams and structures, needs to be supported by the investment from individuals at the core; the individual living with dementia, informal caregivers and the case manager, as well as investment from the wider professional network. As such, these understandings can be used to shape the next iteration of coordinating interventions in dementia care in way that makes them more acceptable to all concerned.

Although the search for the qualitative review was not updated because a manuscript had been accepted for publication in a peer-review journal, I am aware of one study that would have been included in a review update that came to light in the updated search for the meta-analysis and subgroup analysis review. De Lange et al. (2017) [179] conducted an online focus group with professionals to identify facilitating factors for case management in dementia care. The addition of this paper would not have altered the results and their findings were comparable to the ones presented in this review. De Lange et al. (2017) [179] found that good cooperation between care partners, embedding of case managers within organisations, funding, competent case managers and familiarity with case management were key to success. Although the inclusion of this study would not have altered the findings of the review, the addition of a sixth study would have added to the reliability of results.

Strengths and limitations

Evidence for this review was systematically identified, critically appraised and synthesised using the outlined steps for thematic synthesis [144], and has been reported following the PRISMA guidelines [169]. The studies included in the review were of high to moderate quality, so the findings and conclusions carry considerable weight.

This review was original in its aim to address the perspectives and experiences of relevant stakeholders on coordinating interventions in dementia care and their perspectives on key components. A number of systematic reviews have been completed in this area, but have focused on the effectiveness of coordinating interventions [111-116]. However, Khanassov et al. (2014b) [116] included some qualitative evidence in a mixed-studies systematic review that aimed to highlight barriers to implementation. In agreement with some of the review findings, frequently reported barriers included confusion of roles within the service delivery and a lack in communication among the professionals involved. Khanassov et al. (2014b) [116] also reported numerous issues developing from time constraints of case managers' including a change from proactive to reactive care, an issue reflected in the results of this review.

Other findings are consistent with existing qualitative evidence in general dementia care. Hirakawa et al. (2017) [180] found that limited resources such as a lack of time and space for quality dementia care, and a lack of funds for hiring and training interdisciplinary staff were barriers to integrated dementia care. Poor communication with professionals has also been associated with dissatisfaction in care from service users, and thought to influence the level of trust in the therapeutic relationship [181].

Although all included studies focused on community-based coordinating interventions in dementia care, they were based in a variety of countries; UK, Canada and the Netherlands, which could limit the generalisability of findings. It is important to consider the global differences in the structure and funding of health and social care services for the context of intervention delivery. In taking the pragmatic approach [166], I consider the extent to which these context specific findings can be generalised and applied across settings. Based on the World's Bank classification system [182], all three countries are of high income where the state plays a significant role in the running of the health care system. Therefore the countries have broadly comparable health services and any differences in health care provision are unlikely to affect what stakeholders perceive as important in coordinating dementia care. Among the studies synthesised, the CAREDEM trial [84] conducted in

the UK was by far the largest study that was a high quality feasibility trial and provided most of the data. This feature of the review will have increased the relevance of its findings for UK services, though at the expense of its generalisability to other countries.

Another consideration when interpreting the findings of the qualitative review is the level of interpretations already existing within the data. The raw data from each study was not used in the synthesis but rather the researchers' interpretations of the raw data. Thematic synthesis has been criticised for its restriction to themes reported by authors of primary studies, and its limited ability to offer a theoretical framework for higher levels of interpretation [142]. However, Thomas and Harden (2008) [144] argue the transparency of their thematic synthesis method, and its ability to distinguish 'data-driven' descriptive themes, such as the ones identified in this review, from 'theory-driven' analytic themes, that provide an efficient framework for higher levels of interpretation.

Finally, there was a notable difference in the amount of data available for synthesis from service users and that available from professionals, with substantially more data from professionals. Although there is now a movement in health care research for the inclusion of patients and publics throughout the research process, there are a number of potential issues when collecting qualitative data from individuals with dementia that may explain some of the disparity in amounts of data available in this field of research. Firstly, accessing individuals with dementia for recruitment has been described as having several 'gatekeepers' including clinicians, ethics committees and informal caregivers [183]. For recruited participants, obtaining fully informed consent comes with more barriers when working with individuals living with dementia. The traditional competency-based approaches for informed consent are not sufficient in incorporating individuals with dementia and the potential issues around capacity they present. Research lacks transparency on how individuals with dementia have actually been included in the consent process [184].

Implications

Clinical services should consider these intervention components when developing and implementing coordinating interventions in dementia care to help improve the acceptability of

intervention, potentially impacting effectiveness and optimising patient outcomes. Evidence from implementation science suggests that more careful thought at the development and planning stage can lead to better embedding of interventions into practice and a greater chance of success. For example, the Promoting Action on Research Implementation (PARiHS) framework argues the interplay between evidence, context and facilitation will dictate the success of the implementation [185]. Frameworks like PARiHS can be used prospectively to guide decisions about intervention design, implementation and evaluation. PARiHS can be utilised during intervention development to represent the contribution of the nature and type of evidence, the characteristics of the context in which the evidence is being implemented, and the way in which this process is facilitated [180]. The reviewing process outlined within the thesis address the first component of PARiHS in considering the evidence base, and the second component in exploring the current UK NHS context through interviews with relevant stakeholders.

Similarly, the Normalisation Process Theory (NPT) states four main components important for an intervention to become 'normalised' in practice; coherence, engagement, collective action and reflexive monitoring [186]. NPT focuses on the different kinds of work individuals conduct when delivering a new complex intervention. During the initial intervention development, NPT provides a framework for mapping the context of the intervention and defining the individuals and groups involved. Using stakeholders can address questions within the framework including identifying the concerns of the individuals and groups, and determining whether the proposed intervention will address these concerns. For example, the coherence element of NPT focuses on how individually and collectively components of practice are understood and operationalised. In intervention development, relevant stakeholders can be queried on their understanding of the interventions and its components to identify a shared understanding, as well as exploration around the potential demands of the complex intervention and potential benefits to different individuals and groups. NPT framework and its components can be utilised in the early stages of development to explore implementation factors prior to implementation and in later intervention evaluation.

Future trials of community-based coordinating interventions in dementia care need to include detailed process evaluations to capture the further information on stakeholder preferences, issues of implementation and specifics of context. In addition, it is essential that these trials provide detail on the exact content of interventions so they can be replicated, evaluated and compared. Furthermore, the bias in available data from service users and professionals should be addressed. There is increasing evidence that involving service users enhances the suitability and acceptability of interventions, and aids the retention of participants in trials [135]. Systematically seeking input from service users during developmental stages of interventions, and actively seeking feedback in evaluation stages should be a key dimension for future research.

While such qualitative findings are limited in their generalisability, they are useful tools for developing coordinating intervention and more general service development. Following a diagnosis of dementia, service users are in need of guidance and support in navigating dementia services. The review shows that coordinating interventions are valued by both service users, and seen as an acceptable approach to managing treatment.

Further research is needed to determine which of these preferred components are important for the effectiveness of the intervention. The following chapter aims to address this issue by conducting a systematic review and meta-analysis to evaluate the effectiveness of coordinating interventions in dementia care, followed by subgroup analyses to investigate the associations of the identified components within this review with intervention effects.

Conclusion

This synthesis of relevant qualitative studies has shown how various stakeholder groups have clear preferences for components, implementation methods and settings for community-based coordinating interventions in dementia care. By adhering to these preferences when planning and developing models of interventions that coordinate care for individuals with dementia we may increase the likelihood of success in intervention trials and produce more consistent results trial across outcome measures.

CHAPTER 4

The effectiveness of community-based coordinating interventions in dementia care: a meta-analysis and subgroup analysis of intervention components[1]

[1]This chapter is a more detailed version of a published paper. This is in agreement with the Creative Commons Attribution License (CC BY 4.0) that allows authors to share and adapt published intellectual property:

Backhouse A, Ukoumunne OC, Richards DA, McCabe R, Watkins R, Dickens C. The effectiveness of community-based coordinating interventions in dementia care: a meta-analysis and subgroup analysis of intervention components. *BMC Health Services Research*. 2017; 17 (717).

Abstract

Background: Interventions aiming to coordinate services for the community-based dementia population vary in components, organisation and implementation. This systematic review aimed to evaluate the effectiveness of community-based coordinating interventions on health outcomes and investigate whether specific components of interventions influence their effects.

Methods: Four databases were searched from inception to April 2017: MEDLINE (OvidSP), The Cochrane Library, EMBASE and PsycINFO. This was aided by a search of four grey literature databases, and backward and forward citation tracking of included papers. Title and abstract screening was followed by a full text screen by two independent reviewers, and quality was assessed using the CASP appraisal tool. Meta-analyses and subgroup analyses were then conducted using RevMan software.

Results: A total of 14 randomised controlled trials (RCTs) involving 10,372 participants were included in the review. Altogether 12 meta-analyses and 19 subgroup analyses were carried out. Meta-analyses found coordinating interventions showed a statistically significant improvement in both patient behaviour measured using the Neuropsychiatric Inventory (NPI) (mean difference (MD) = -9.5; 95% confidence interval (CI): -18.1 to -1.0; p= 0.03; number of studies (n)=4; I^2= 88%) and caregiver burden (standardised mean difference (SMD) = -0.54; 95% CI: -1.01 to -0.07; p= 0.02; n=5, I^2= 92%) compared to the control group. Subgroup analyses found interventions using a case manager with a nursing background showed a greater positive effect on caregiver quality of life than those that used case managers from other professional backgrounds (SMD= 0.94 versus 0.03, respectively; p<0.001). Interventions that did not provide supervision for the case managers showed greater effectiveness for reducing the percentage of patients that are institutionalised compared to those that provided supervision (odds ratio (OR)= 0.27 versus 0.96 respectively; p=0.02). There was little evidence of effects on other outcomes, or that other intervention components modify the intervention effects.

Conclusion: Results show that coordinating interventions in dementia care have a positive impact on some outcomes, namely patient behaviour and caregiver burden, but the evidence is inconsistent and results were not strong enough to draw definitive conclusions on general effectiveness. With the rising prevalence of dementia, effective complex interventions will be necessary to provide high quality and effective care for patients, and facilitate collaboration of health care, social care and third sector services.

Key words: Dementia, health services, dementia care coordination, case management, systematic review, meta-analysis, collaborative care, community interventions

Introduction

This chapter follows the outlined approach of an exploratory sequential review in which qualitative evidence is synthesised first [139]. In the previous chapter, I reviewed qualitative evidence on the perspectives and experiences of stakeholders on coordinating interventions in dementia care and their views on the perceived key components. The findings showed how various stakeholder groups considered care coordinating interventions as acceptable, useful and appropriate for dementia care, and have clear preferences for components, implementation methods and settings of these interventions.

Five independent studies incorporating the views of over 100 stakeholders were included in the thematic synthesis [144] that identified five overarching descriptive themes from 32 codes associated with effective care; (1) *Case Manager*: preferences for the case manager personal and professional attributes, including a sound knowledge in dementia and availability of local services; (2) *Communication:* the importance stakeholders placed on multichannel communication with service users, multidisciplinary teams (MDT) and organisations; (3) *Intervention*: focused primarily on the contact type and frequency between case managers and service users, and the importance of case manager training and service evaluation; (4) *Resources:* outlined stakeholder views on the required resources for coordinating interventions and potential overlap with existing resources; and (5) S*upport:* reflected the importance that was placed on the support network around the case manager and the investment of professionals involved directly in care as well as the wider professional network.

A manuscript of this review has been published in BioMed Central Health Services Research journal [187]. This chapter is a more detailed version of the manuscript published. Due to the word limitations of peer-reviewed journals, the manuscript was restricted in its detail. I have extended some of the methods sections to provide justification that may not be required in peer-reviewed journals, and have added to the discussion section for a more comprehensive discussion of the research within the context of the thesis.

Objectives

I aimed to evaluate the effectiveness of coordinating interventions in dementia care through conducting a systematic review with a meta-analysis of RCTs. I then aimed to investigate whether there is any evidence that potentially key components of the interventions, identified by stakeholders in the qualitative review, modify intervention effects on health outcomes of individuals living with dementia and their informal caregivers.

Methods

The review protocol was registered with PROSPERO (registration: CRD42015024618) and published in a peer review journal [138] in accordance with the criteria in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement for systematic reviews [169].

Eligibility criteria

Types of studies: Studies were eligible for inclusion if they were RCTs of community-based interventions coordinating care in dementia. Non-randomised experimental studies such as those with a before-and-after or quasi-experimental design were excluded.

Types of participant: Included studies involved participants with a dementia diagnosis of any type who were living in the community, with no restrictions on age or gender. Studies were excluded where they involved individuals who did not have a formal diagnosis of dementia or who had self-defined as having dementia due to the uncertainty of diagnosis in such participants. Additionally, studies were excluded if they focused solely on informal caregivers and did not include a focus on increased care coordination or improved outcomes for individuals living with dementia.

Types of intervention: Included interventions were delivered by a single, identified professional who took responsibility for the provision and management of care. The main focus of their role was described in the study report as planning, facilitating and/or coordinating care through assessments and proactive follow-ups.

Control: Comparators included 'usual care', standard community treatment, alternative dementia care interventions or waiting-list controls.

Setting: Included studies were interventions that were based in the community. Studies based in hospitals or nursing and residential homes were excluded, as were those that involved changes made to health care systems or application of guidelines alone.

Types of outcome measures: All available binary and continuous outcome measures related to individuals living with dementia and/or their informal caregiver were considered.

Date, Language and Location: No restrictions were placed on date, language or study location.

Information sources and search strategy

As the initial review protocol outlined a mixed studies systematic review, one search process was conducted covering both qualitative and quantitative evidence (see Appendix 1).

Electronic searches: The following four electronic databases were searched from date of inception to June 2015, with the search syntax being modified appropriately for the individual database: MEDLINE (OvidSP), The Cochrane Library, EMBASE and PsycINFO. Electronic searches were updated in April 2017.

Additional resources: Four additional databases were searched for unpublished studies; the Health Management Information Consortium (HMIC), Social Policy and Practice (SPP), ProQuest and the International Clinical Trials Registry Platform (ICTRP). Backward and forward citation searches were completed on included studies and relevant systematic reviews identified in the screening process.

Search strategy: A comprehensive search strategy was developed through consultation with the PenCLAHRC evidence synthesis team, information on terminology from a prior scoping review of the literature and search strategies of relevant identified published systematic reviews. The search based on the outlined eligibility criteria used a combination of controlled vocabulary specific to the individual database (e.g. MEDLINE Medical Subject Headings (MeSH terms)) and free text terms. A master search strategy can be found in Appendix 1.

Study selection

Data management: All references were managed in EndNote X7.0.2. Titles and abstracts of studies identified in the initial search were imported into EndNote, followed by full texts of potentially relevant papers for further screening. Duplicates were removed automatically by EndNote, and assisted by a subsequent hand search.

Screening: Title and abstract screening was followed by a screening of potentially relevant full texts, and was conducted independently by myself and a colleague (RW). A member of the supervisory team was available for any screening disagreement.

Data extraction

A bespoke data extraction sheet designed using Microsoft Office Excel and piloted on three RCTs. Data were extracted on study design, participant characteristics, methodology, intervention characteristics, comparator group(s) and outcome measures.

For the subgroup analysis, data were also extracted on intervention components identified by stakeholders as potentially important in influencing treatment effects. The review of qualitative evidence (see chapter three) identified 32 codes that were grouped into five descriptive themes. RCTs were initially searched for all 32 codes forming the basis of 'components'. However, some codes were not tangible or had not been measured in trials. Therefore the following intervention components were identified for subgroup analyses, and are presented with the details of how the trials were categorically grouped:

1. ***Case manager base*** – i.e. the working location of the case manager, either in community or non-community (e.g. primary care) settings
2. ***Case manager professional background*** – nursing background or non-nursing background
3. ***Case manager training*** – specifically trained for the case manager role or not
4. ***Contact frequency*** – how often the case manager was in contact, grouped as those with low contact frequency (less than or equal to the median across studies of 14.4 contacts per 12 months) and high contact frequency (more than 14.4 contacts per 12 months).

5. ***Contact type*** – mode of contact (i.e. telephone, face-to-face or written) used to communicate with individuals with dementia and their caregivers

6. ***Supervision*** – whether or not the case manager had been assigned a mentor or supervisor during the intervention

7. ***Workload*** – case manager caseload, divided at mean number of patients per case manager across studies (51.1), into those with high caseload (more than 50 patients) and low caseload (less than or equal to 50 patients).

Information on intervention components was initially sought in all of the published material for each included trial. Systematic reviews that had included trials were also scrutinised for information on intervention components that could not be identified in original trial papers. If information on components could not be found in trial reports or published systematic reviews then study authors were contacted in an attempt to obtain this information. Both first authors, and additional paper authors were contacted. If information on intervention component could not be found through any of these sources then component was marked as *not reported* (NR) and could not be included in the subgroup analysis.

Results of studies represented in multiple papers are included in the review once to avoid double counting. For trials with more than one associated paper, the primary paper has been cited as the main reference though data were extracted from all available papers. Authors were approached via email to obtain missing data. Missing standard deviations (SD) were calculated from standard errors of the mean (SEM) or SDs were obtained from other studies.

Risk of bias

The Critical Appraisal Skills Programme (CASP) RCT appraisal tool [188] was used to assess the quality of included trials. The checklist includes 11 questions covering rigour, research methods, relevance and research integrity. Myself and a colleague (RW) independently assessed the quality of included trials, and disagreement was resolved through discussion.

Data synthesis

Descriptive statistics were used to summarise main study characteristics and the risk of bias.

Meta-Analysis: Random-effects meta-analyses of RCTs were conducted using Review Manager 5.3. Random-effects meta-analyses were selected over fixed-effect meta-analyses because of the methodological heterogeneity across trials. For continuous outcomes, standardised mean differences (SMD) were pooled, except when change scores and final scores were combined in which case the mean difference (MD) was pooled. For binary outcomes, odds ratios (OR) were pooled. For the purpose of this meta-analysis, where specific outcomes were measured across multiple time points, the result nearest the median time point for that outcome was used. Heterogeneity across studies was quantified using the I squared (I^2) statistic which calculates the percentage of variation across studies that is due to between-study heterogeneity as opposed to chance [189].

Subgroup analysis: Trials were grouped based on the presence or absence of intervention components identified, as outlined above. Intervention effects were estimated within subgroups and compared across subgroups to identify components for which the size of the effect depends on whether they are present; in other words, to identify components associated with the intervention effects.

Results

Study selection

The original search identified 2,718 citations, and an updated search performed in April 2017 identified a further 381 records for screening. A total of 191 citations underwent an independent full-text screen by myself and a colleague (RW), and of those full texts 35 papers from 14 RCTs were included in the final review (see Appendix 3). A full report of the selection process can be found in the PRISMA diagram in Figure 4.

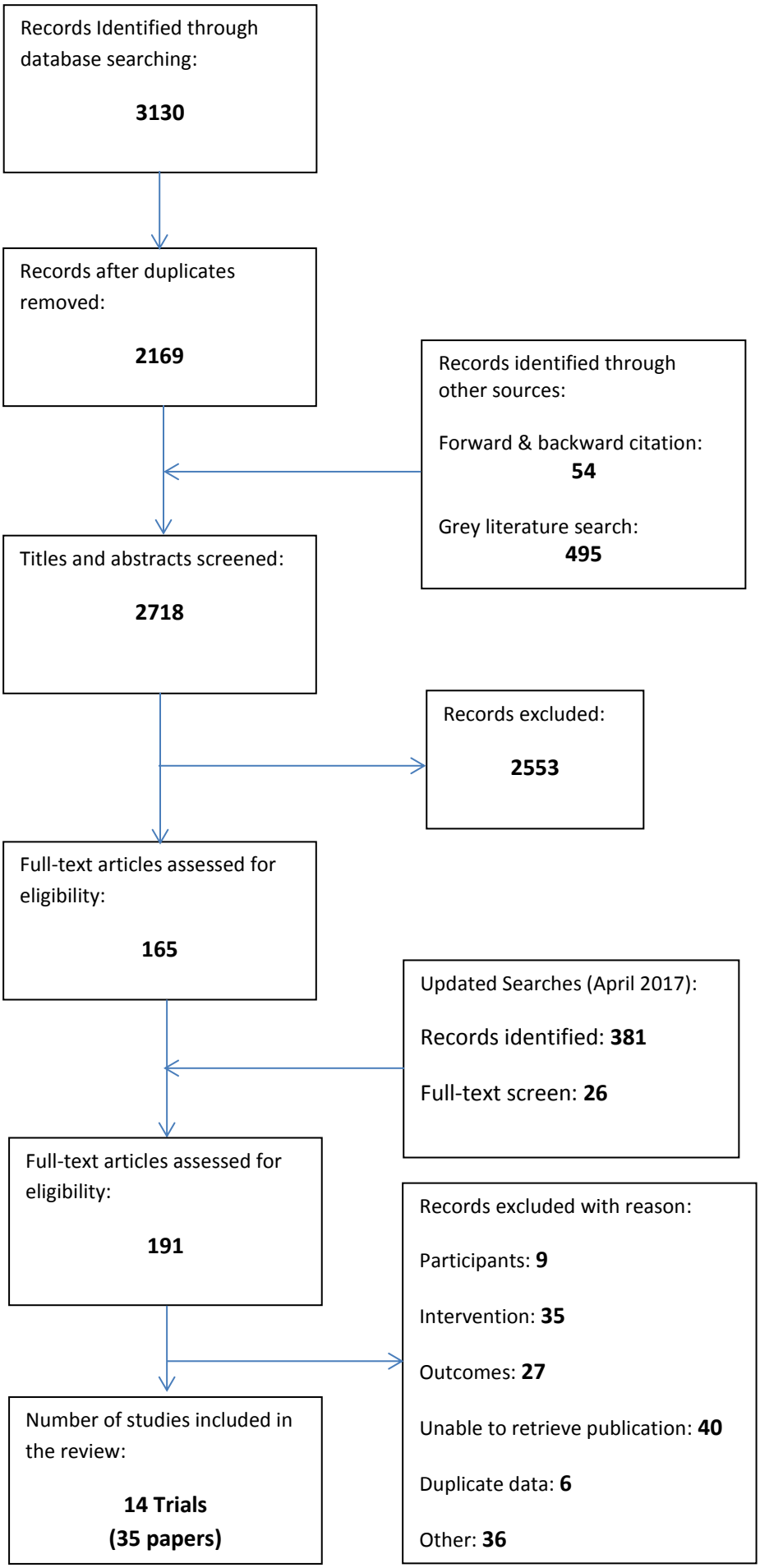

Figure 4: PRISMA diagram for selection process of studies for meta-analyses and subgroup analyses

Study characteristics

Of the 14 trials, six were based in the USA [86, 125, 127, 131, 190, 191], three in China [126, 192, 193], two in Finland [85, 132], and one each in the Netherlands [124], India [87] and Canada [134]. In total, the trials included 10,372 participants, with 8,095 recruited from one trial [125]. Three trials randomised clusters (e.g. general practice) [127, 131, 191] and 11 [85-87, 124-126, 132, 134, 190, 192, 193] randomised individuals. The duration of the trials ranged from 4 months to 3 years. Trial characteristics are summarised in Table 5.

Eight of the trials had case managers based in community teams [86, 87, 124, 126, 190-193], two trials used case managers in both community and primary care teams [125, 127], in two trials case managers were based in primary care [85, 131] and two trials did not report case manager base [132, 134]. Six trials used a nurse as a case manager [85, 124, 131, 132, 192, 193], four trials used social workers [86, 134, 190, 191] and two trials used a combination of the two [125, 127]. One trial used an occupational therapist [126]. Nine trials reported on specified training around the role for case managers [85, 87, 124, 127, 132, 190-193], four did not report any training [86, 125, 126, 134] and only one trial clarified no training [131]. All but two of the trials used both face-to-face and telephone contact as forms of communication between case managers and service users, with two trials using telephone contact only [86, 127]. Of the 14 trials, seven reported providing supervision to case managers [86, 87, 125, 127, 131, 132, 190], four trials did not report on supervision [124, 126, 134, 191] and three clearly stated no supervision was provided [85, 192, 193]. Further details of trial components can be found in Appendix 4.

Table 5: A summary of characteristics of trials included in the meta-analyses and subgroup analyses

Study ID	*Country*	*Randomisation unit*	Sample Size		*Intervention duration*	*Length of follow-up*
			Intervention	Control		
Bass 2003	USA	Individual	94	63	12 months	12 months
Bass 2014	USA	Clinic	316	192	12 months	12 months
Callahan 2006	USA	Physician	84	69	12 months	18 months
Chien 2008	China	Individual	46	46	6 months	12 months
Chien 2011	China	Individual	44	44	6 months	18 months
Chu 2000	Canada	Individual	37	38	18 months	18 months
Dias 2008	India	Individual	41	40	6 months	6 months
Eloniemi-Sulkava 2001	Finland	Individual	53	47	2 year	2 year
Eloniemi-Sulkava 2009	Finland	Individual	63	62	2 year	2 year
Jansen 2011	The Netherlands	Individual	54	45	12 months	12 months
Lam 2009	China	Individual	59	43	4 months	12 months
Newcomer 1999	USA	Individual	4151	3944	NR	36 months
Samus 2014	USA	Individual	106	183	18 months	18 months
Vickrey 2006	USA	Clinic	238	170	4-16 months	18 months

**NR – not reported*

Risk of bias

All of the trials were rated as high or moderate quality, and all had used appropriate methods for randomisation and were therefore free of selection bias. On this basis, no studies were excluded due to quality, and results of the full CASP appraisal can be found in Appendix 5.

Results of synthesis

Binary outcomes included hospitalisation (whether or not the patient was admitted to hospital), institutionalisation (whether or not the patient was admitted to a residential or nursing home) and mortality. Continuous outcomes for individuals living with dementia included quality of life, behaviour, cognition, depression and function. Continuous outcomes for caregivers included quality of life, mood, burden and social support. Forest plots for each comparison can be found in Appendix 6.

Meta-analysis: Six missing SDs were calculated from the SEM and two missing SDs were obtained from other studies. Coordinating interventions showed a statistically significant improvement in both patient behaviour measured using the NPI (MD = -9.5; 95%; confidence interval (CI): -18.1 to -1.0; p= 0.03; number of studies (n) =4; I^2= 88%) and caregiver burden (SMD = -0.54; 95%; CI: -1.01 to -0.07; p= 0.02; n=5, I^2= 92%) compared to the control group (See Table 6). There was only weak evidence of effects on institutionalisation (OR= 0.60; 95% CI: 0.32 to 1.11; p= 0.10; n=9; I^2= 48%), caregiver mood (SMD= -0.04; 95% CI; -0.10 to 0.01; p=0.10; n=6; I^2= 0%), caregiver quality of life (SMD= 0.45; 95% CI: -0.03 to 0.94; p= 0.07; n= 4; I^2= 89%) and social support (SMD= 0.38; 95% CI: -0.08 to 0.84; p= 0.10; n=3; I^2= 81%), and little evidence of effects for hospitalisation (p=0.50), mortality (p= 0.73), patient quality of life (p= 0.35), patient cognition (p= 0.40), patient depression (p= 0.48) or patient function (p= 0.46).

Table 6: Results of the meta-analyses exploring effects of coordinating interventions on binary and continuous outcome measures

Outcome Measure	*Number of trials included*	*Follow-up time point range*	*Odds Ratio*	*95% CI*	*I^2*	*P Value*
Hospitalisation	6	12-18 months	0.89	0.64 to 1.25	0%	0.50
Institutionalisation	9	10-12 months	0.60	0.32 to 1.11	48%	0.10
Mortality	9	6-12 months	0.97	0.81 to 1.16	0%	0.73

Outcome Measure	*Number of trials included*		*Standardised Mean Difference*	*95% CI*	*I^2*	*P Value*
Patient Quality of Life	3	12 months	0.09	-0.09 to 0.27	0%	0.35
Patient Cognition	4	12 months	-0.09	-0.29 to 0.11	0%	0.40
Patient Function	3	6 months	-0.08	-0.30 to 0.14	0%	0.46
Caregiver Burden	5	6-18 months	-0.54	-1.01 to -0.07	92%	0.02
Caregiver Mood	6	6-18 months	-0.04	-0.10 to 0.01	0%	0.10
Caregiver Quality of Life	4	9-12 months	0.45	-0.03 to 0.94	89%	0.07
Social Support	3	12 months	0.38	-0.08 to 0.84	81%	0.10

Outcome Measure	*Number of trials included*		*Mean Difference*	*95% CI*	*I^2*	*P Value*
Patient Behaviour	4	12 months	-9.52	-18.05 to -1.00	88%	0.03
Patient Depression	3	9-12 months	0.60	-1.08 to 2.27	66%	0.48

CI Confidence intervals; *I^2* I squared statistic; *MD* Mean difference; *SMD* Standard mean difference

Subgroup analysis: Interventions using a case manager with a nursing background showed a greater positive effect on caregiver quality of life compared to those that used case managers from other professional backgrounds (SMD= 0.94 versus 0.03, respectively; p<0.001). Interventions that did not provide case managers with supervision showed greater effectiveness for reducing the percentage of patients that are institutionalised compared to those that provided supervision (OR= 0.27 versus 0.96 respectively; p=0.02). There was weak evidence that interventions using a lower caseload for case managers had greater effectiveness for reducing the number of patients institutionalised compared to interventions using a higher caseload for case managers (OR= 0.23 versus 1.20 respectively; p= 0.08). There was little evidence that the other intervention components modify treatment effects (see Table 7).

Publication bias: Publication bias was explored using funnel plots (Appendix 7). Institutionalisation and mortality were the only two outcome measures to show a positive result in publication bias; the results of neither were statistically significant in the meta-analysis of overall intervention effect.

Table 7: Results from subgroup analyses exploring intervention components associations with effects

Outcome Measure	*Subgroups*	*Number of Trials Included*	*Odds Ratio*	*95% CI*	*I^2*	*p Value**
Hospitalisation	Community base	2	1.21	0.70 to 2.08	0%	
	Non-community base	4	0.74	0.48 to 1.13	0%	
	Subgroup difference					0.16
	Nursing background	4	0.96	0.58 to 1.60	9%	
	Non-nursing background	2	0.81	0.51 to 1.31	0%	
	Subgroup difference					0.63
	High contact	2	0.49	0.19 to 1.30	0%	
	Low contact	3	0.97	0.61 to 1.53	19%	
	Subgroup difference					0.22
	Supervision	3	0.99	0.60 to 1.62	19%	
	No supervision	3	0.78	0.47 to 1.30	0%	
	Subgroup difference					0.52
	Low workload	4	0.74	0.48 to 1.13	0%	
	High workload	2	1.21	0.70 to 2.08	0%	
	Subgroup difference					0.16
Institutionalisation	Community base	4	0.50	0.16 to 1.61	37%	
	Non-community base	2	0.93	0.09 to 9.06	70%	
	Subgroup difference					0.64
	Nursing background	6	0.44	0.20 to 0.95	23%	
	Non-nursing background	2	0.69	0.10 to 4.98	49%	
	Subgroup difference					0.67
	High contact	3	0.38	0.11 to 1.34	39%	
	Low contact	3	1.05	0.21 to 5.18	43%	
	Subgroup difference					0.33
	Supervision	3	0.96	0.47 to 1.95	26%	
	No supervision	3	0.27	0.12 to 0.61	0%	
	Subgroup difference					0.02
	Low workload	2	0.23	0.08 to 0.67	0%	
	High workload	3	1.20	0.27 to 5.32	37%	
	Subgroup difference					0.08
Mortality	Community base	4	0.74	0.36 to 1.51	0%	
	Non-community base	2	1.71	0.55 to 5.30	0%	
	Subgroup difference					0.22
	Nursing background	4	1.44	0.65 to 3.15	0%	
	Non-nursing background	3	1.42	0.48 to 4.22	0%	
	Subgroup difference					0.99
	High contact	2	0.62	0.23 to 1.65	25%	
	Low contact	4	1.50	0.55 to 4.10	0%	
	Subgroup difference					0.22
	Low workload	2	0.50	0.18 to 1.36	0%	
	High workload	3	1.26	0.52 to 3.03	0%	
	Subgroup difference					0.17

Outcome Measure	*Subgroups*	*Number of Trials Included*	*SMD*	*95% CI*	I^2	*p Value**
Patient Cognition	Community base	2	0.06	-0.23 to 0.35	0%	
	Non-community base	2	-0.21	-0.49 to 0.06	0%	
	Subgroup difference					0.18
Caregiver Burden	Supervision	2	-0.78	-1.69 to 0.14	96%	
	No Supervision	2	-0.24	-0.49 to 0.02	0%	
	Subgroup difference					0.27
Caregiver Mood	High contact	2	-0.05	-0.11 to 0.00	0%	
	Low contact	4	0.01	-0.13 to 0.16	1%	
	Subgroup difference					0.41
Caregiver quality of life	Nursing background	2	0.94	0.63 to 1.25	0%	
	Non-nursing background	2	0.03	-0.32 to 0.39	89%	
	Subgroup difference					<0.001

Outcome Measure	*Subgroups*	*Number of Trials Included*	*MD*	*95% CI*	I^2	*p Value**
Patient Behaviour	Low workload	2	-13.24	-28.23 to 1.75	95%	
	High workload	2	-5.40	-10.63 to -0.17	0%	
	Subgroup difference					0.33

CI Confidence intervals; I^2 I squared statistic; *MD* Mean difference; *SMD* Standard mean difference
*p value is for the subgroup comparisons

Discussion

Summary of evidence

The results from the meta-analyses of 14 RCTs demonstrated that coordination interventions have an effect on a variety of health-related outcomes, as measured by both binary and continuous measures. The effects of coordinating interventions appear to be a reduction in caregiver burden and improvements in patient behaviours as measured using the NPI.

Of the intervention components that were analysed, case manager professional background and supervision were the only components for which there was evidence of association with the intervention effect. Case managers with a nursing background, as opposed to other professional backgrounds such a social work or occupational therapy, are associated with improved caregiver quality of life and lack of an identified supervisor for case managers is associated with a greater reduction in institutionalisation rates. The difference in effect sizes found in the analysis are considered large, and therefore likely to be clinically significant based on the criteria set out by Cohen [194].

The meta-analyses findings are consistent with previous reviews [111-114] of coordinating interventions in dementia care in painting a varying and complex view of the effects these interventions have on patient and caregiver outcomes. The subgroup analyses are consistent with findings of Bower et al. (2006) [195], who reported that in trials of collaborative care for depression the specific mental health background of case managers predicted improvements in depressive symptoms. However, the finding that no supervision was associated with a greater reduction in institutionalisation was inconsistent with Bower's [195] finding that providing supervision also predicted improvements in depressive symptoms.

There are several potential explanations for this inconsistent finding. It is possible that standard line management was in place for individuals taking on the case manager roles in trials which could have been a sufficient supportive structure for the role. Alternately, it may be that the focus is on timeliness and appropriateness of institutionalisation rather than delaying

institutionalisation, a topic that was discussed in the *'intervention'* theme of the qualitative synthesis. Supervision could have the potential to empower case managers to facilitate institutionalisation and empower families to make the decision on institutionalisation. Therefore measuring the rate of institutionalisation would not necessarily show effect. Despite inconsistent results in the subgroup analysis of supervision, it is an important structure and standard practice not just in coordinating interventions but in many clinical roles [196].

Although previous research has highlighted that stakeholders have preferences in the structure, delivery and components of coordinating interventions, there is little evidence to support the notion that incorporating the preferences will have a positive impact on patient and caregiver outcomes. However, it is possible this is a function of the trial design, and that the included trials had not intentionally set out to include stakeholder preferences. A purposeful inclusion of preferences and orientation of interventions towards preferences may show more success.

Strengths and limitations

Evidence for this review was systematically identified, critically appraised and synthesised using the standardised steps for meta-analysis and subgroup analysis, and has been reported following the PRISMA guidelines [169]. The trials included in the review were of high to moderate quality, so the findings and conclusions carry considerable weight.

Authors were contacted for missing information that was not included in the trial reports, including information on the relevant intervention components for subgroup analyses. However, there was still substantial variability in the outcome measures recorded, the intervention structures and the reporting of the necessary intervention components which meant that only a small number of trials could be included in many of the meta-analyses and subgroup analyses. As a result, the confidence intervals for the intervention effect are often wide indicating that no effect or at the other extreme a larger effect are both plausible truths for some outcomes. Furthermore, although seven components were sought and recorded, due to the limited number of trials and available information, only five of these seven components could be tested in subgroup analyses.

Furthermore, it is important to remember that subgroups are not based on randomisation and are therefore observational in nature which increases the likelihood of identifying false positive or false negative significant effects. Subgroup analysis also has the potential for confounding variables, where the component tested is closely related to another component or characteristic [197].

Although trials were grouped and effects compared based on trial inclusion of a specific component, the nature of a given component at times still differed across trials. For example the case manager caseload varied from 1:20 to 1:125, and although the subgroups were categorised as high caseload (more than 50 patients) and low caseload (less than or equal to 50 patients), the variability within these groups could be seen as relatively large. Another example of potential variability is the experience, clinical setting, career level and demographic characteristics of having a nursing professional background. Potential methods for addressing heterogeneity on a continuous level include meta-regression, but this was not possible due to the limited number of trials and data available. More detail on the selection of subgroup analysis can be found in chapter two under rationale for meta-analyses and subgroup analyses. However, this variability within intervention components across trials needs to be considered and caution taken in the interpretation of the results. There is room in the subgroup analyses findings to explore the more detailed specifics of the intervention components which can be done using qualitative research methods.

Heterogeneity is also a consideration when interpreting meta-analyses findings. A random-effects model was used which considers heterogeneity in the analysis, but does not remove it. Since clinical and methodological heterogeneity will always occur to some extent in a meta-analysis [198], the I^2 was used to measure true heterogeneity that is not due to chance. Statistical heterogeneity was identified in some of the results that showed a high I^2 statistic (>75%). However, the subgroup analyses were pre-specified and aimed to explore some of the heterogeneity between studies used in the meta-analyses.

The quality of the included trials varied but the majority used appropriate methods for randomisation and were therefore free of selection bias. Due to the nature and complexity of coordinating interventions, most of the participants and professionals involved in the interventions were not blinded leading to potential detection bias. This issue was reduced in the majority of trials through the use of self-report measures, service use data or a blinded external data collector. There was an indication of potential publication bias for two outcome measures, suggesting there is a possibility that smaller trials that found negative results were not published.

Implications

From the results of this meta-analysis, and existing systematic reviews [111-114], evidence for coordinating interventions in dementia care can improve some outcomes for individuals with dementia and caregivers. There is room to address the differences in coordinating intervention models in order to clarify and synchronise their aims, structure and implementation.

The results from subgroup analyses could have interesting implications for future design of coordinating interventions. Using case managers with a nursing background and assigning a low caseload, such as a maximum of 50 patients per case manager, in new coordinating interventions could be beneficial for implementation and outcomes. Institutionalisation showed a statistically significant effect in one subgroup analysis. Therefore incorporating institutionalisation in the postulated outcomes of coordinating interventions and implementing components with a focus on facilitating appropriate institutionalisation could help improve the success of intervention trials.

A key message from this review is the importance of future trials of any complex intervention to be rigorous in their design and implementation, and focus on high quality reporting not only of research methods but of the intervention details. It is important that a comprehensive description of the content and delivery of interventions reported to allow replication and comparison across trials.

One additional consideration is how patient and public involvement and engagement (PPIE) could have been utilised in the review process, and the importance of using PPIE in future systematic

reviews. PPIE could have been utilised in the reviewing process to ensure that the review questions were important to relevant stakeholders and that the outcome measures being assessed were of relevance to the target population. Furthermore, PPIE can be used to ensure the findings of reviews are relevant and accessible to individuals affected or responsible for making decisions in dementia care, and then utilised in practice. To some extent the inclusion of review findings in the conceptual model and the discussion of the model with relevant stakeholders incorporates some aspects of PPIE in validating findings. However, early inclusion of PPIE from the start of the reviewing process would have been beneficial and should be utilised in future reviews of any nature.

Conclusion

The results of this review have shown that coordinating interventions have some positive impact on selected outcome measures, namely caregiver burden and patient behaviour. Including case managers with a nursing background can improve caregiver quality of life. The differences across models of coordinating interventions in dementia care are substantial and this has made it difficult to identify what should be considered core components. Although there are challenges to the implementation of coordinating interventions, addressing those and incorporating more stakeholder preferences early in design may produce more consistent results and increase the likelihood of success. With the rising prevalence of dementia, it is likely that complex interventions will be necessary to provide high quality and effective care for patients, and facilitate collaboration of health care, social care and third sector services.

In the following chapter I aim to incorporate these findings in a new conceptual model for coordinating care in dementia.

CHAPTER 5

Development of a conceptual model for a coordinating intervention in dementia care

Chapter outline

Following the synthesis of qualitative and quantitative evidence in previous chapters, in this chapter I aim to present a conceptual model for a coordinating intervention and explain the process by which it was developed. Presented in this chapter are:

- An introductory section on issues surrounding development of complex interventions
- A description of the methods and processes by which the conceptual model was developed
- A diagram of the conceptual model, followed by a clear outline and detail of the model contents
- A discussion on the development of the model for coordinating care and reflection on the strengths and limitations of the development process

Introduction

In chapter one I discussed the complexity of coordinating interventions in dementia care and the involvement of numerous interacting components embedded within complex and changing health and social care systems. Chapter one contains descriptions of the mounting research over the past few decades in coordinating interventions, which although has shown some promise, has failed to produce a standardised intervention model to allow for replication of research or to help develop an understanding of the relationships between context, intervention components and intended outcomes.

In chapters three and four I evaluated the evidence base for coordinating interventions specifically in dementia care through two sequential systematic reviews. Thematic synthesis of qualitative evidence that revealed stakeholder groups considered care coordinating interventions as acceptable, useful and appropriate for dementia care, and have clear preferences for components, implementation methods and settings of these interventions. However, although meta-analyses of data showed coordinating interventions to have some potential for positive impact on selected outcome measures, only five of the 32 codes could be used in subgroup analyses. This meant that

only a few preferred components identified in the qualitative synthesis proved to have a significant association with intervention effect in the subgroup analyses.

In this chapter I aim to use the findings from chapters three and four to inform the development of a conceptual model for a coordinating intervention that targets individuals with dementia living in the community. Conceptual models are used to develop, understand and simulate a complex intervention addressing a public health issue, in this case dementia [199]. A clear conceptual model should define intervention components and how they relate to, and impact, on each other and on the hypothesised outcomes within a defined context. Furthermore, a conceptual model should describe a set of assumptions of how an intervention is supposed to work and the outlined activities that should be responsible for bringing about change [200].

The modelling process and outcomes is the final step in the development stage of the MRC framework [135], and has been described as 'abstract and remote'. Complex interventions have been considered a 'black box' problem in that when they are successful it is difficult to understand why and therefore difficult to replicate, and when they are unsuccessful they are hard to 'fix'. Furthermore, as we have seen in the reviewed evidence, complex interventions can often generate some overall significant effect, but optimising this is problematic, and the variability in success is due to the variation in contexts and constraints [148]. These are issues that should be addressed form the start when developing a complex intervention [199].

Furthermore, an inadequate development of an intervention prior to a clinical trial can contribute to research waste. As with many complex interventions, trials of coordinating interventions have produced inconsistent, inconclusive and unreplicable results [111-116]. Although research waste, estimated to be around 85%, has focused on issues with poorly formed research questions, insufficient use of prior evidence, badly designed trials and poor reporting and intervention description [201], it is hypothesised that inadequate development of interventions contributes its fair share to research waste [147]. Therefore defining the actual intervention in the development phase is a vital step that will allow us to standardise the content and delivery in a

shared language and vision for coordinating interventions in dementia care, something that has been lacking from previous literature.

In keeping with the MRC framework [135], I have used the reviewed evidence from chapters three and four to inform the modelling process. Consulting the relevant literature has helped clarify the intervention and has led to identification of important components, as well as likely facilitating factors and barriers to implementing such an intervention. Another important yet difficult aspect of modelling a complex intervention is the selection of the most appropriate outcome measures to assess the effectiveness of the intervention. As well as identifying these outcomes, models must outline the processes by which the intervention may achieve these effects [202]. It is important that measured outcomes encompass the interests of professionals involved in deciding on or delivering the intervention and the service users' affected by it. Like the intervention components, the outcomes should be determined a priori and informed by relevant stakeholders' perspectives and the evidence base [203].

Although the MRC framework [135] emphasises the importance of reviewing theory and evidence and then modelling interventions, detail on guidance for research and methods in these phases is lacking. Many of the available reporting guidelines for complex interventions in health care, such as the Template for Intervention Description and Replication (TIDieR)[149], are useful in improving the transparency and potential replication of interventions but they do not lend detail or guidance in the development process or how interventions can be refined before succession for clinical trials [147].

With this in mind, I used a combination of literature to guide the development process of the coordinating intervention and followed the steps of the Centre for Community Health and Developments Community Tool Box framework for developing a logic model [150]. This framework identifies the links between resources, intervention components and effects. The initial steps in this framework are to identify the purpose of the intervention and to outline the context; the purpose is the motivation for change, or the problem the intervention is addressing, while the context outlines

the necessary conditions in which the intervention takes place. These are followed by the resources required for the intervention to be carried out, and the intervention components including specified activities for each component and the outputs that are direct evidence of having performed activities. The final element is the effects of the intervention known as the primary, intermediate and long-term outcomes of the intervention. Assembling these elements into a diagram gives the basic structure of a conceptual model that will visually represent the workings of the coordinating intervention for dementia care. A simplified diagram of the generic Community Tool Box framework can be found in figure 5.

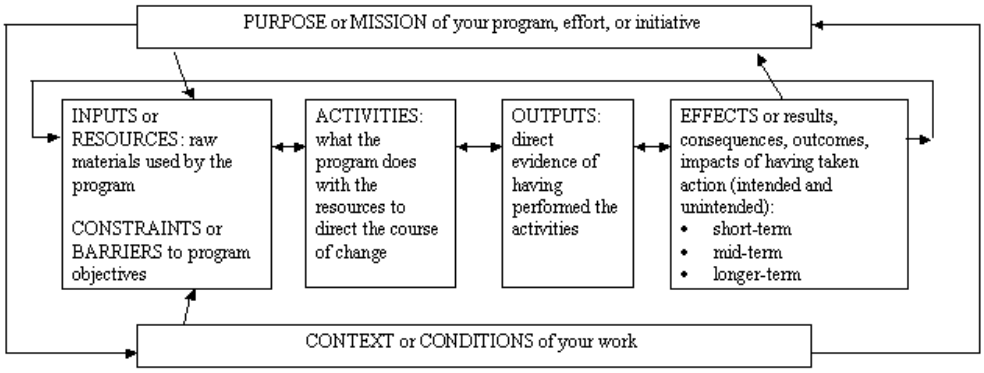

Figure 5: The Community Tool Box generic framework for development of logic model

Methods

Evidence from the review of qualitative research, and evidence from the meta-analysis and subgroup analysis, formed the basis of the conceptual model of the coordinating intervention. This was supported by information in general literature and policy.

Evidence from quantitative synthesis

Of the 32 components identified in the qualitative synthesis, seven were reported and measurable in trials but only five were included in subgroup analyses. A small number of identified trials and difficulty finding the information about each component within trial reports inhibited some of the subgroup analyses. However, where subgroup analysis had found an identified component of coordinating interventions showing a significant association with an intervention outcome, then this component was included in the conceptual model. These components will have

strong reliability because they have been identified within qualitative synthesis as valued by stakeholders, and also tested within statistical synthesis.

Evidence from the qualitative synthesis

Of the 32 components identified in the qualitative synthesis, 25 were not reported or measurable in trials and a further two were not able to undergo subgroup analyses due to the small number of trials. For these components, I referred back to findings from the qualitative synthesis to inform those aspects of the conceptual model. Components that were entered into the subgroup analyses but did not show any significant between group differences, i.e. no component modified effect; I refer back to the qualitative findings to address preferences of stakeholders.

Evidence from general literature and policy

Furthermore, some of the model components are supported by information gathered in the general literature around coordinating interventions and policy in dementia care that has been discussed in chapter one. Where review results were weak, in that they were reliant solely smaller findings from the qualitative review, then evidence was sought out to support these findings. Where findings were conflicting, such as in the case of supervision, further evidence was sought to clarify the component. Policy was more commonly referred to for components that required detail structure, such as care plans and supervision. Here policy papers were referenced as an indication of component structure and requirements. The strength of support for these components found only in the qualitative review results and/or in literature will be lower.

Hierarchy of evidence

There is a hierarchy of evidence that is used to inform the development of the conceptual model. I firstly relied on components that were identified in the qualitative synthesis and had shown a significant association with intervention effects in the subgroup analysis. Following which I relied on the findings of the qualitative synthesis. Where the model needed more structure, the final source of evidence came from general literature and policy. In terms of strength of evidence, components found in the qualitative synthesis and associated with effect will have the strongest

base, those based in the qualitative synthesis findings have relative strength, and those solely found in the general literature and policy have the weakest evidence base.

Results

Following the Community Tool Box framework [150], I have outlined the resources, intervention components and their related activities and outputs, and finally the postulated intervention outcomes. Each section is accompanied by a table that displays a mapping process to demonstrate the evidence for each aspect of the model. Evidence is described in four forms; qualitative review findings, quantitative review findings, general literature and policy.

Resources

Inputs are required from professional partners, care partners and training requirements. Professional partners include the case manager, the GP and a supervisor. The case manager will be the primary resource at the centre of the intervention working in partnership with the individual with dementia and caregiver. The case manager will have a nursing background, as the subgroup analyses found an association with a positive effect on caregiver quality of life.

Resources was identified as a theme in the qualitative review, and I have drawn on information provided from the data within this theme to further inform the necessary resources for the intervention. Qualitative evidence on the case manager was substantial, and stakeholders were clear they should have strong interpersonal skills, good knowledge of dementia and local community services. Interpersonal skills were seen as important in aiding the development of the therapeutic relationship which was vital for service users' investment in the intervention.

Subgroup analyses comparing trails using community based case managers to trials using non-community based case managers found no significant differences between groups, suggesting no advantage of either base. Despite qualitative findings indicating that neither service users nor professionals showed a preference for the base of case managers, it was clear that primary care nurses were pressured for time and found it difficult to protect the case manager role. Some

professional stakeholders felt that a primary care based nurse may medicalise the intervention, and may also lack comprehensive knowledge of local community services which is vital to the case manager role. In light of these results, the case manager will be a nurse based in the Community Mental Health Team (CMHT) whose remit of care includes individuals living with dementia [204].

From the qualitative review stakeholders were unclear on the role of the GP, but emphasised the importance that the GP should be involved and invested in the intervention. This will be facilitated through communication (face-to-face, telephone and written) with the case manager to receive updates on patients when required. It is also important to keep the GP involve in care as they will remain the primary medication prescriber to patients, as required by the British Medical Association GP committee [205].

Subgroup analysis indicted interventions that did not provide case managers with supervision showed greater effectiveness for reducing the percentage of patients institutionalised compared to those that provided supervision. Discussion around understanding this finding is in detail in the summary of evidence discussion section of chapter four. However, qualitative synthesis suggested supervision is a key aspect of coordinating interventions and a component that was valued by professional stakeholders. Supervision is also a common component in many coordinating intervention models and is relevant in many clinical roles. It has been supported by the Nursing and Midwifery Council for the use of continued improvements in clinical practice and professional development through reflective practice. Although no standardised model is followed for clinical supervision, the Royal College of Nursing among other institutions have guidance documents [206]. Furthermore, there is evidence for supervision improving clinical practice. Edwards et al. (2006) [207] found that effective clinical supervision for community based mental health nurses in the UK led to lower levels of burnout and reduced likelihood of negative feelings towards clients. On this basis, I have decided to include supervision as a component in the conceptual model.

Qualitative evidence reported the importance of a supportive MDT that will come from embedding the case manager within an existing CMHT. Professionals within the team must show

investment in the intervention, with a willingness to participate and support the case manager. Investment and collaboration also has to come from the wider professional network. Although the case manager will be in the secondary care sector, they will be linked with primary and tertiary health care teams, social care and third sector organisations. The case manager will facilitate communication and collaboration across sectors.

The final resource is the required training for case managers' prior to beginning the role to build on existing knowledge and skill set, and to clarify the boundaries of the role and ensure minimal duplication of care. The amount of training time allocated to case managers' is based on previous trials of coordinating interventions in dementia: the PREVENT trial in the USA [131] and its UK implementation in the CAREDEM feasibility trial [84]. In these trials, eight 2 hour sessions are used for specific training of case managers'. I have included this as two days, or 16 hours, of training. Stakeholders in the qualitative review also reported professionals' confusion over the coordinating interventions and the case manager role, which was thought to lead to a lack in support and investment. Therefore I have included a section for the training of necessary professionals who have close involvement in the intervention with an aim of clarifying the purpose of the intervention and case manager role, and facilitating investment from those professional stakeholders. See Table 8 for more details.

Table 8: Shows the resources required for the intervention and details on the source of the evidence

	Resources			
Level	***Input***	***Model detail***	***Source of evidence***	***Detail of evidence***
Professional Partners:	Case Manager	Nursing professional background	Quantitative review & qualitative review	Trials using case managers with a nursing background had a greater positive effect on caregiver quality of life ($p<0.001$). Stakeholders in the qualitative review felt a nurses were more familiar to service users, had a more direct link to GPs and could address comorbidities
		Based within the Community Mental Health Team (CMHT)	Qualitative review & policy	Primary care was seen by review stakeholders to have high time constraints for nurses, and community based professionals could offer respite from these clinical settings. NHS guidelines for the CMH services include services for individuals with dementia [204]
		Good interpersonal skills	Qualitative review	*Interpersonal skills* was a code within the case manager theme. Traits such as kindness and empathy were seen to help improve development of therapeutic relationship and ease sensitive discussions
		Knowledge of dementia	Qualitative review	*Case manager knowledge* was a code within the *case manager* theme. A sound knowledge of dementia was seen to assist case managers in advising on practicalities and uncertainties of the illness
		Knowledge of local services	Qualitative review	*Case manager knowledge* was a code within the *case manager* theme. A sound knowledge of local services (health, social and third sector) were seen to aid in tasks such as signposting and referrals

	General Practitioner (GP)	Remains primary medication prescriber	Qualitative review & policy	*GP investment* was a code in the *support* theme. GPs were seen to remain involved in care of patients and should therefore be involved in coordinating intervention. British Medical Association General Practitioners Committee (2015) [205] outlines GPs specific clinical rights and responsibility in prescribing
		In regular contact with case managers and receive updates regarding patients	Qualitative review and literature	*GP investment* was a code in the *support* theme. GPs were seen to remain involved in care of patients and should therefore be involved in the coordinating intervention. Cochrane best practice for case managers (2011) [208] outlines the importance of working with GPs in three ways; patient prioritisation, care plan and impact assessments
	Supervisor	Senior member of CMHT	Qualitative review & Policy	Policy documents suggest a standard of practice in which it is a senior member of staff that takes up the supervisory role [206, 209]
		Supportive and provides guidance	Qualitative review & policy	The *supervision* code within the *support* theme discusses the role as a mentor for guidance, help with case reviews and encouraging integration of case managers. Policy and guidance documents on supervision in clinical practice also describe a supportive and guiding role [210]
Care Partners:	CMHT Primary health care Secondary health care Social care Third sector organisations	Coordination of the health care, social care and third sector services for individuals living with dementia at home	Qualitative review, literature & policy	The *communication* theme of the qualitative review describes the inclusion of multidisciplinary teams and communication across organisations from all sectors. This is echoed in the literature [80, 211] and in policy documents [118, 212]

Training:	Specific case manager training	Training across 16 hours/ 2 days	Qualitative review & literature	The importance of case managers receiving role specific training was outlined in the *case manager training* code under the *case manager* theme. The estimation in amount of training is based on current literature including the PREVENT trail [131] in the USA and its UK implementation in the CAREDEM trial [84]
	Continued professional development	Self-directed learning	Qualitative review & literature	In the qualitative review, stakeholders discussed the issues around case managers identifying their own educational needs. There is evidence around the importance of self-directed learning in professional development [213]
		Educational needs assessment	Qualitative review	Educational needs assessment was discussed in the *case manager training* code, and was thought to be the responsibility of both the case manager and the supervisor
	Brief training on dementia care coordinating intervention for health and social professionals involved	Introductory seminar and training information pack	Qualitative review & literature	In the *communication* theme the *role understanding* and *goals and aims* codes described the difficulty of other professionals in understanding the intervention. There was a need for consistency across teams and the wider professional network. Evidence in the literature echoes this and suggests strategies for maintaining continuity of care and getting other professionals on-board [118]

Intervention components; activities and outputs

The intervention components outlined drew on information in the *intervention* theme of the qualitative review. Stakeholders were in general agreement about a selection of tasks case managers' should be completing and these have been listed as; identifying patients for coordinating intervention, comprehensive assessment, planning and organisation of care, responsive care, follow-up assessments, evaluation and communication. These components are described in more detail in the conceptual model, with accompanying activities for each component and outputs to enable the tracking of each component.

There was general agreement in the qualitative review findings that the intervention should be offered at the point of diagnosis. This early interaction was seen as a facilitating factor in the development of the therapeutic relationship, which was important to both service users and professionals. There was weak evidence to suggest that a lower caseload (≤ 1:50) for case managers' was associated with a reduction in institutionalisation rates. The latter is consistent with results from the qualitative synthesis where stakeholders felt higher caseloads increased the time constraints of the case manager. The case manager will have a maximum of 50 patients, but this will likely go under review later as it is the top end of the 'low caseload' group.

The assessment, planning and responsive components were findings from the qualitative review, but are also present as standard components of many coordinating interventions and general health care interventions which were discussed in chapter one [118, 214]. Assessment of both the individual living with dementia, and where present the informal caregiver were important to identify needs and develop a care plan agreed upon by service users. The first assessment will be comprehensive, and cover physical, psychological and social needs. The proactive nature of the case manager, and their need to be available and flexible in care was important to stakeholders in the qualitative review, and is also aligned with the movement of person-centred care in current literature and policy [215, 216].

Subgroup analysis comparing trials using high contact frequency (equal to or above 14.4 contacts per 12 months) between case manager and service users and trials using low contact frequency (below 14.4 contacts per 12 months) found no significant differences between groups, suggesting no advantage of either contact frequency group. Based on qualitative findings, contact frequency will be dependent on the needs of the service users but should be at regular intervals. Findings from the qualitative review suggest maintaining regular contact with service users was again beneficial for the therapeutic relationship.

After initial assessments and care plan, qualitative review findings suggest scheduled follow-up assessments are important to monitor the changing needs of service users. To further monitor the general success of the intervention and implementation an evaluation strategy that includes meetings, feedback, reports and appraisals was seen as important. Professional stakeholders in the qualitative review described a need to provide evidence of effectiveness and a clear trail of activity, elements I have incorporated in the model.

The final component in the model is communication and is heavily based on the *communication* theme from qualitative review. The review found that a lack in communication on aspects such as the overarching goals and aims of the intervention were a barrier to effective implementation, therefore facilitating communication could lead to a greater, shared understanding of the role and intervention. *Communication* was a broad theme that spanned individual communication between the case manager and individuals living with dementia and caregivers, as well as across large, MDTs and across organisations from all care sectors. I have tried to capture this in the model by incorporating meetings with relevant professionals from MDTs and other health care, social care or third sector professionals where necessary. The inclusion of a MDT and the wider care network is supported by evidence in the literature that describes MDTs as supportive structures, as well as policy that outlines the necessity of cross-sector working in care [217, 218]. See Table 9 for more details.

Table 9: Shows the intervention components and details on the source of the evidence

Intervention component	*Model detail*	*Source of evidence*	*Detail of evidence*
Participants	Defining individuals who are eligible to receive the dementia care coordinating intervention	Literature	This has been the initial aim of the intervention following reviewing the literature in chapter one
Identification	Case manager is assigned at the point of diagnosis	Qualitative review	In the *illness trajectory* code of the *intervention* theme there was a general consensus that the case manager should be available from point of diagnosis
	Maximum caseload 1:50	Qualitative review & literature	There was some evidence in the qualitative review of stakeholders suggesting a maximum caseload of 1:50. This was also the mean number of patients per case manager across trials in the meta-analyses. There was weak evidence from the subgroup analysis that lower caseload was associated with lower rates of institutionalisation
Assessment	Assessment of individual with dementia and, where necessary, assessment of informal caregiver	Qualitative review	The *intervention* theme included discussions around the importance of the health and well-being of the caregiver as well as the individual with dementia
	Formulation of the care plan	Qualitative review & policy	Care plan was one of the tasks agreed by stakeholders in the *intervention* theme of qualitative review. It is also a standard practice in many policy papers [118, 219]

Planning	Being proactive in planned contact, both face-to-face and telephone contact	Qualitative review	The *contact frequency* and *contact type* codes were in the *intervention* theme alongside the *proactive* code. Face-to-face contact was important for developing a therapeutic relationship, and telephone contact was seen as necessary for brief follow-ups and when time was restricted
	Flexible to the needs of service users	Qualitative review & literature	Results from the qualitative review suggest stakeholders felt contact frequency and type should be dependent on service users' needs. There is substantial literature around the need for interventions to be flexible for service users in order to move towards person centred care [118, 214], which is echoed in policy papers [220]
Responsive	Ad-hoc or unscheduled contact from service users	Qualitative review & literature	In the *intervention* theme, stakeholders discussed the importance of service users feeling comfortable to make contact with case managers when needed and this contact could facilitate proactive care. Other models of care coordination in the literature describe the 'availability' of case manager [78, 80, 92, 221]
Follow-up assessments	Scheduled follow-up assessments every 6 months	Qualitative review & literature	In the *identifying needs* code of the *intervention* theme, follow-up assessments were seen as necessary to identify and keep track of service users' needs. Routine follow-ups are also standard in many models aiming to coordinate care, and 6 month follow-ups appear to be a common time point in dementia literature [78, 80, 92, 221].

Evaluation	Evaluation strategy including meetings, feedback, reported intervention activities and appraisals	Qualitative review	*Evaluation* was a code of the *intervention* theme that focused on successful implementation of the intervention, with professionals stakeholders indicating a need for evidence of effectiveness, and a clear trail of activity
Communication	Clear overarching goals and aims	Qualitative review	*Communication* was a theme from the qualitative review that emphasised the importance of clear and regular contact between care partners and service users, and a need for clear overarching goals and aims of the intervention to facilitate implementation and collaboration
	Multidisciplinary team meetings	Qualitative review, literature & policy	*MDT* was a code in the *communication* theme seen as an important feature of coordinating interventions, with meetings and regular feedback seen to facilitate team working. Involving a MDT with effective working has been shown to improve implementation [222, 223]. This collaborative working is encouraged by policy documents [217]
	Meetings with relevant professionals from health care, social care and third sector organisations	Qualitative review, literature & policy	As well as a MDT, having strong links across health care, social care and third sector organisations was seen as important in the *communication* theme, which should be facilitated by appropriate and timely meetings. Cross-sector working has supportive evidence [215] and is encouraged by policy documents [224].

Outcomes

The outcomes of the intervention are outlined at two levels; service user level and system level, and are described in terms of primary, immediate and long-term outcomes. A key aim of coordinating interventions is to improve the general coordination of care for services users through the use of case managers, and facilitating communication and collaboration across professional networks [62, 218, 225] and aiding service users to navigate a broad system of care. In the conceptual model, for service users this is described as aiming to improve the pathway of care so that the health and social care systems, alongside the third sector function better for the individual with dementia and their families.

Findings from the qualitative synthesis reported a focus on the health and wellbeing of service users. In light of this, I have based outcomes for individuals living with dementia and informal caregivers on health-related outcome measures included in the meta-analyses some of which have shown intervention effect; e.g. patient quality of life, patient behaviour, patient cognition, patient depression, patient function, caregiver quality of life, caregiver depression and caregiver burden.

Service user and professional satisfaction of care were discussed in the qualitative review and thought to be an important and appropriate outcome so have been included in the model. Furthermore, findings in the qualitative review indicate the importance of investment from all partners involved in the intervention, and I have therefore included an outcome of aiming to improve the value that both services users and professionals place on dementia care coordination.

Timely and appropriate use of resources was a topic within the *resource* theme of the qualitative review, with many stakeholders feeling that the lack of coordination in the care system was leading to unnecessary use of resources such as GP appointment times, unplanned hospital admissions and respite care. Therefore, by coordinating care through the use of case managers, the intervention aims to improve the timely use of resources by service users and the appropriate utilisation of resources by professionals. Institutionalisation was a particular resource of discussion in the qualitative review, and enabling the individual to live safely at home was seen as the most

appropriate focus of coordinating interventions. Rather than aiming to delay institutionalisation as long as possible, the case manager should facilitate the transition to homes when this was necessary. With this in mind, case managers will have good working relationships with local care, nursing and residential homes.

Finally, the findings from the qualitative review reveal a need to move beyond the measurable outcomes of an intervention, and look at the broader approach to care. Some of the qualitative review data report on the need to take a more person-centred and holistic approach to care, which is echoed in many health and social care policy documents that focus on delivering person-centred care [215, 216]. I have included this as a long-term, system level aim of the intervention. See Table 10 for more details.

Table 10: Shows the postulated intervention outcomes and details on the source of the evidence

Level	*Outcome*	*Model detail*	*Source of evidence*	*Detail of evidence*
Service users: Primary	Improving the care pathway	Improve the pathway of care so that the health and social care systems, and the third sector function better for the individual with dementia and their families	Literature & policy	One of the overarching aims of many coordinating interventions in that services function better for service users, and the care pathway is clear and accessible. Literature and reports suggests this is currently fractured and confusing for service users [62, 219, 225]
	Improved health related outcomes for patient	Outcomes: patient quality of life, patient behaviour, patient cognition, patient depression & patient function	Qualitative review & literature	There was a consensus in the qualitative review that the focus should be on the health and wellbeing of service users. Specific outcome measures were selected from quantitative review of trials
	Improved health related outcomes for caregiver	Outcomes: caregiver quality of life, caregiver depression & caregiver burden	Qualitative review & literature	There was a consensus in the qualitative review that the focus should be on the health and wellbeing of service users. Specific outcome measures were selected from quantitative review of trials
	Increased value of dementia care coordination	To increase the willingness to participate, and improve service user investment in and value of the intervention	Qualitative review	Investment from all parties involved in care was key to the support theme, and was thought to facilitate communication

Service users: Intermediate	Service users care satisfaction	Improving the function of the care system should help to improve service users' satisfaction and experience of care	Qualitative review	Service users and professionals satisfaction with care were discussed in the *outcome measures* code of the *intervention* theme, and were thought to be an appropriate measures in care coordinating interventions
	Improved timely use of resources	Service users should increase the appropriate use of other resources including care such as; GP appointment times, unplanned hospital admissions, respite care and crisis response teams	Qualitative review & literature	The *resource* theme discussed the resources required for successful implementation, including appropriate and timely use of resources. There is also evidence for the need to improve the allocation of health and social care resources [214]
Service users: Long-term	Enable independent living	Enable individuals to live in their own homes for as long as is seen appropriate	Qualitative review & quantitative review	In the *outcome measures* code of the *intervention* theme, stakeholders expressed concern that delaying institutionalisation was not necessarily the correct aim of interventions, but rather to focus on enabling the individual to remain at home for as long as is safe and appropriate, at which point the case manager should facilitate transition. Coordinating intervention did show a small, non-significant effect of delaying institutionalisation which could suggest an issue in timing
	Facilitate institutionalisation	When institutionalisation is the most appropriate step, the case manager should help facilitate and coordinate the transition	Qualitative review	

System level: Primary	Improved communication across services	Facilitate and improve communication across all levels of care; health care, social care and third sector services	Qualitative review & policy	The *communication* theme from the qualitative review emphasised the importance of facilitating communication across all care sectors. Key documents have also outline the importance of communication when working together across various different sectors [218]
	Reduced time constraints of case managers	Aim to reduce the time constraints previously seen in case manager roles	Qualitative review	In the qualitative review, time constraints of case managers were seen as a barrier to many intervention activities including communication and collaboration
	Increased value of dementia care coordination	By involving a wide variety of professionals and services, dementia care coordination could increase the value and investment placed in the care model	Qualitative review	Investment from all parties involved in care was key to the support theme, and was thought to facilitate communication
System level: Intermediate	Professionals satisfaction	Improve health care professionals' satisfaction with care services and their working environment	Qualitative review	Service users and professionals satisfaction of care were discussed in the *outcome measures* code of the *intervention* theme, and were thought to be appropriate measures in care coordinating interventions
	Improved utilisation of resources	A reduction in unnecessary use of services and other resources, and avoid unscheduled use of crisis interventions, as well as improving the timeliness of services	Qualitative review	The *resource* theme discussed the resources required for successful implementation, including appropriate and timely use of resources. There is also evidence for the need to improve the allocation of health and social care resources [214]

System level: Long-term	Improved collaboration of care services	Facilitate collaboration across health and social care, and third sector services by improving communication and coordination	Literature	This has been the initial aim of the intervention following reviewing the literature in chapter one
	Holistic approach to community based care	A more person-centred and holistic approach to community based care in dementia	Qualitative review & policy	In the *goals and aims* code of the communication theme, stakeholders spoke of the need to move beyond measurable outcomes and a need to aim towards a holistic approach to care. This is echoed in the person-centred focus of health and social care policy [216, 226]

A conceptual model for a coordinating intervention in dementia care

Figure 6 is a visual representation of the key coordinating role the case manager plays and indicates the focus on services users; the individual living with dementia and informal caregiver. The case manager sits in the central position with service users with the aim of emphasising the role of coordinating care between various different services and sectors of care. The arrows in the diagram depict two-way communication between various care partners across sectors, and the case manager and service users. However, it is important to note that the communication and collaboration expected in the intervention is not refined to the arrows and partners depicted in the diagram. Communication is intended to be two-ways with all care partners in the wider professional networker, and is likely to be dependent on the needs of the service users. This complexity could not be depicted in a simplified model.

Figure 7 shows the final model illustrating the resources, intervention components, activities, outputs and outcomes of the proposed dementia care coordination intervention. Box 1 is the output that describes each element of the model in detail. This is the first draft of the model and will be presented to stakeholders in the next chapter of my thesis.

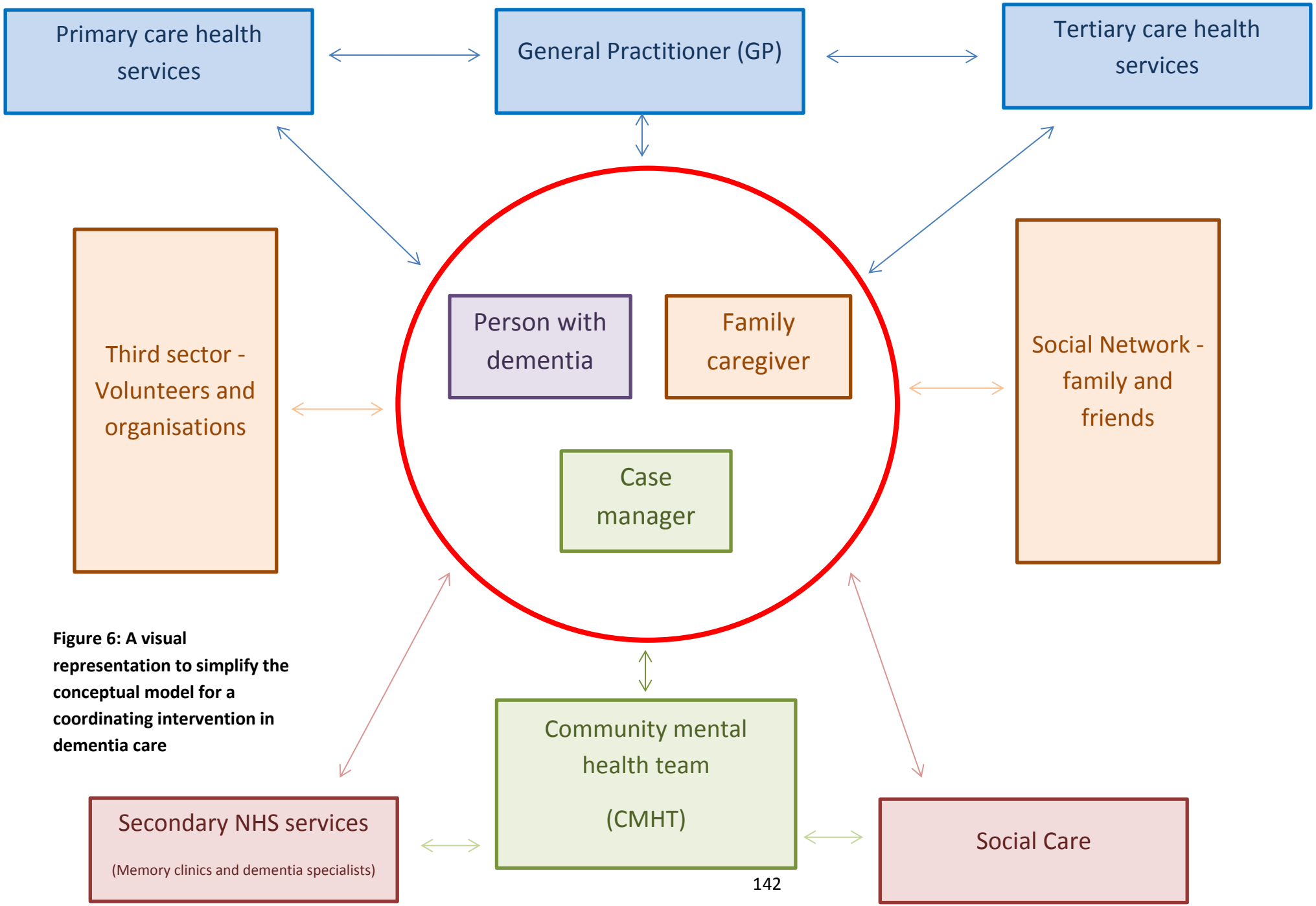

Figure 6: A visual representation to simplify the conceptual model for a coordinating intervention in dementia care

RESOURCES

Professional Partners:
- Case manager
- General Practitioner
- Supervisor

Care Partners:
- Community mental health team
- Primary health care
- Secondary health care
- Tertiary care
- Social Care
- Third sector organisations

Training:
- Specific case manager training
- Continued professional development
- Brief training on dementia care coordinating intervention/ model of care for health and social care professionals directly involved (GP, supervisors)

OUTCOMES

Service users-level

Primary:
- Improving the pathway of care
- Improved health related outcomes for patient
- Improved health related outcomes for caregiver
- Increased value of dementia care coordination

Intermediate:
- Service users care satisfaction (person with dementia and carer)
- Improved timely use of resources

Long-term:
- Enable independent living
- Facilitate institutionalisation

System level

Primary:
- Improved communication across services
- Reduced time constraints of case managers
- Increased value of dementia care coordination

Intermediate:
- Professionals satisfaction
- Improved utilisation of resources

Long-term:
- Improved collaboration of care services
- Holistic approach to community based care

INTERVENTION COMPONENTS	**ACTIVITIES**	**OUTPUTS** *Evidence of activities*
Participants	• Individuals diagnosed with dementia • Disease severity • Their informal caregivers	• Increased number of individuals in dementia care coordination
Identification	• GP referral to memory clinic • Dementia diagnosis • Case manager assignment	• Patient record updated with diagnosis
Comprehensive assessment	• Individual with dementia assessment • Caregiver assessment • Care plan	• Patient record updated • GP informed of assessment results • Documented care plan
Planning	• Contact frequency • Contact type	• Record of contact with patient and/or caregiver
Responsive	• Unscheduled contact with case manager	• Record of ad hoc contact • Record of contact with other services
Follow-up assessments	• Interval follow-up assessments	• Patient record updated • GP informed of assessment results • Documented • Care plan modified
Evaluation	• Management evaluation strategy; including appropriate meetings, feedback, reported intervention activities, appraisals.	• Management evaluation strategy document • Record of strategy components addressed e.g. appraisals
Communication	• Clear statement describing overarching goals and aims of dementia care coordinating intervention • Multi-disciplinary team meetings • Meetings with relevant professionals across health care, social care and third sector organisations	• Dementia care coordination mission statement • Documented minutes and action points from meetings

Figure 7: A conceptual model for a coordinating intervention in dementia care

Box 1: Conceptual Model of coordinating care in dementia

Purpose: The purpose of the coordinating intervention is to ensure that individuals living with dementia and their families receive a seamless process of care, with the high quality care and support in the timeliest fashion. The intervention is designed to be proactive in aligning services across all care sectors allowing individuals to live at home for longer while sustaining a good quality of life for both the individual living with dementia and their informal caregiver. Following diagnosis, individuals will be assigned a case manager who will act as a single point of contact, taking responsibility in the provision and management of care through planning, facilitating and coordinating care services appropriately. The case manager will work collaboratively across health and social care services, and with the third sector to ensure a seamless care pathway for each individual.

Context: Individuals who have been diagnosed with dementia who are living in the community, and where appropriate their informal caregiver.

RESOURCES:

Case Manager: The case manager is the central professional in the intervention and is key to the coordinating care for service users. The case manager will be a qualified nurse based in the community mental health team (CMHT) and will act as the primary contact for service users with the role of planning, facilitating and coordinating care for service users. The case manager will work collaboratively with all partners involved in the care of the service user, including informal caregivers, family members and all relevant professionals.

In order to achieve the aims of dementia care coordination, the case managers must have particular skills and knowledge. Case managers will have strong interpersonal skills, demonstrating an ability to be warm, understanding and empathetic. These skills will be useful in developing a strong therapeutic relationship with service users. With a nursing background the case manager will not only coordinate care but will also be able to perform care tasks themselves where possible, have an understanding of medical issues and comorbidities, and communicate effectively about the

service users' medical status. Other skills include, but are not limited to, a commitment to and investment in building a therapeutic relationship with service users and working relationships with professionals, good written and verbal communication and the ability to plan and organise effectively.

The case manager will have a fundamental knowledge in dementia so they can enable service users to manage the practicalities and uncertainties of the illness, and will have access to multidisciplinary support from the CMHT allowing them to call upon specialists or intensive treatments when needed. This will include a basic knowledge of dementia-related issues including behaviour changes, potential illness trajectory and key characteristics of the disease. Case managers will also have a sound knowledge of available local dementia and age related services to facilitate signposting and referrals.

GP: The General Practitioner (GP) plays a key role in the service users' health care and is the gatekeeper to the health care system. It is therefore important the GP is involved in the coordinating intervention. The GP will be the main person responsible for the prescription of medication and will play a key role in assessing and managing comorbidities. The GP will primarily be in contact with the case manager to receive updates on the service users' medical condition, which will include results of assessments, a formulated care plan and information on referrals. The contact between the GP and case manager will be on a regular basis through email or telephone contact for updates, but face-to-face meetings will only be as and when required.

Supervisor: The case manager will be assigned a supervisor who will be a senior member of the CMHT and responsible for acting as a supportive and mentoring contact. Contact with the supervisor will be on a regular basis, but is flexible to the needs of the case manager. The supervisor will aid in individual case reviews, assessing the training and educational needs of the case manager, encouraging integration of case manager within the existing team, and providing a guiding role in dementia care coordination.

Care partners: The CMHT will be the immediate team in which the case manager is based. The Care partners will include relevant local primary, secondary and tertiary health care teams as well as social care and third sector organisations. The CMHT is a community-based multi-disciplinary team who will work collaboratively to optimise the service user outcomes, and support the case manager working to facilitate communication within the team as well as across care partners.

Regular meetings will take place with the immediate CMHT where necessary health care professionals can be updated on dementia care coordination progress and any case-specific issues can be discussed. Meetings across different organisations will be set up as and when required or case managers can attend relevant existing meetings with care partners. Through developing a network of connections across services, the case manager will be able to signpost service users efficiently and can make timely and appropriate referrals. Regular contact within and across teams will act as a supportive structure to the coordinating intervention, and will facilitate shared learning and resources leading to a more collaborative, holistic approach to care.

Training: The case manager will receive specific training before beginning the role. A total of 16 hours (or two days) training will be an induction to dementia care coordination and the case manager role within the intervention, and will also build on the existing skills and knowledge of candidates. This training will also cover issues around dementia care including potential for difficult cases. Continued professional development is vital and will be encouraged through self-directed learning and access to training guided by educational needs assessment. Following assessments, appropriate training or referral to necessary resource will be conducted to maintain and develop skills and knowledge. Working across the boundaries of different disciplines and services will also offer an opportunity for professional development.

The CMHT as well as other health care professionals involved in the care process will require some basic training on the coordinating intervention and the role of the case manager. Training will be available for these professionals in the form of an introductory seminar and a training/

information pack. There is potential for health care professionals to provide case managers with training where needed for example; using patient information record systems.

ACTIVITIES AND OUTPUTS:

The case manager and other professionals will carry out a number of tasks in the coordinating intervention process. The continuation or completion of these tasks will be demonstrated by specific outputs.

Activity: *Participants*; criteria outlined for potential service users of dementia care coordination are individuals who have received a diagnosis of dementia and are currently living in the community and, where appropriate, their informal caregivers. This service will not cover hospital patients or nursing/residential home occupants.

Output: A record will be kept to monitor individuals coming through the system, being assigned a case manager and receiving dementia care coordination services. The enrolment process will be clearly documented as well as collection of relevant information on the individual with dementia and, where present, the informal caregiver.

Activity: *Identification*; when symptoms have been flagged to the GP potential service users will follow the standard diagnosis process which usually involves an initial referral to a memory clinic where further assessments can be done. Individuals will be identified and referred to dementia care coordination based on the outlined criteria. Following the confirmed diagnosis of dementia of any type individuals will be assigned a case manager and an initial meeting between the case manager, individual living with dementia and informal caregiver will be booked at point of diagnosis. The case manager will have a maximum caseload of 1:50.

Output: The patient's record system will be updated with the diagnosis alongside information on enrolment on the coordinating intervention and the case manager assignment.

Activity: *Assessment*; case manager will visit the service users home to complete an initial comprehensive assessment of both the individual with dementia and, where necessary, the informal caregiver. This will identify the physical, psychological and social needs of the service users, taking

into account the cultural and linguistic needs of each individual. The comprehensive assessment should allow the case manager to develop an understanding of the home situation and conduct a detailed analysis of care needs.

Following the assessment, a detailed care plan will be developed tailored to the individual needs of each service user. The plan will cover physical, psychological and social needs, and will be developed in collaboration with the individual living with dementia, and where present, the informal caregiver. It is important in this stage that the case manager engages and involves services users as partners in decision making for present and future care as an ethical consideration in the person-centred ethos of care coordinating interventions. Approaching care planning with the involvement of service users also aims to facilitate a strong therapeutic relationship.

Output: Documentation of assessment results and the developed care plan. The patient record system and the patients GP will updated with the results of the assessment and subsequent care plan. The case manager, the GP and the individual with dementia and caregiver will hold a copy of the care plan.

Activity: *Planning*; the case manager will be proactive in their role making regular, planned contact with the service users. The contact frequency will be largely based on the needs of the service users, but regular agreed follow up will be arranged either by telephone or visit. Initial assessments will be conducted face-to-face as will some of the following visits to help develop and maintain the therapeutic relationship between service users and case managers. Following these contacts, the type of contact (i.e. telephone, face-to-face) will be determined by the needs of the service users and the schedule of the case manager. The case manager will oversee the delivery of the care plan and the scheduling of contact, allowing for flexibility as the complexity of service users' care needs change and increase. The case manager will arrange services with other care partners, staying in contact with them, aligning care planning and sharing feedback on services from service users.

Output: A specified review record will be held, and will be reviewed as part of scheduled supervision. Case managers' will also keep a full record of all contact with service users through case notes. Any action points resulting from these contacts will be documented and GP will be informed. It will be the responsibility of the case manager to assign action points and follow-up these action points.

Activity: *Responsive:* the case manager will also be responsive in their role; so will be available for unscheduled contact from service users.

Output: A record will be kept of unscheduled contact with the case manager as well as a record of contact with additional services. These records will be in addition to the scheduled contact records.

Activity: *Follow-up assessments*; the case manager will employ continued monitoring through follow-up assessments to manage the response to the care plan and any further requirements of the service users. The follow-up assessments will be in addition to scheduled contacts, and will occur on a six monthly basis unless otherwise necessary. Adjustments to the care plan will be made in collaboration with the individual living with dementia and their informal caregiver.

Output: The care plan will be modified in light of results from follow-up assessments, with further action points, signposting and referrals made as necessary. The patient record system and the GP will be updated with assessment results and care plan modifications where necessary.

Activity: *Evaluation*; a systematic and ongoing strategy will be in place to evaluate the benefits of this model and for quality assessment of care. This will include evaluation of: follow-up assessments to modify the care plan; appraisal of case manager to identify areas of improvement as well as training and educational needs; multi-disciplinary meetings to discuss implementation issues within and across teams; standardised outcomes for service users and professionals; costs of dementia care coordination.

Output: An evaluation strategy outlining general monitoring processes will be documented before care coordinating intervention begins. Records will be kept of evaluation components addressed.

Activity: *Communication*; the case manager will facilitate communication with service users and the relevant care partners in health and social care, and third sector services. Continued efficient communication will take place through appropriate and timely meetings with relevant professionals and care partners, as well as other forms of contact including telephone calls, emails and letters. Meeting with the CMHT should occur on a weekly basis to allow professionals within the team to discuss diagnostics and potential service users, care assessments and plans, evaluations, complications and care transitions. Meetings with other care partners will occur as and when needed in accordance with the service users' care needs, for example to discuss and evaluate service users' care progress, potential changes to care, potential joint visits or to explore solutions to challenges.

Care partners will be encouraged to signal and communicate changes in the service users' situation when necessary. Encouraging these interactions will build strong professional relationships across care providers, and ensure stakeholders are clear on their roles and the aims of the dementia care coordinating intervention. Furthermore, this aims to increase the collaboration and integration of care services. It is important that the case manager maintains a person-centred approach to care, and makes clear communication with service users regarding care and contact with other services.

As the coordinating care will aim to facilitate individuals to live comfortably in their own homes until a time when institutionalisation is necessary, at which point the case manager will facilitate transition to appropriate care home. It is important that the case manager has contact and working relationships with local care homes. The case manager can then act as a placement coordinator at the appropriate time.

Output: An initial dementia care coordination mission statement describing the overarching aims of the care model and implementation activity. The roles of the case manager and other

stakeholders will be clearly defined, setting the professional boundaries of each role. This will be presented in an introductory dementia care coordination meeting for the CMHT. Minutes and action points will be recorded from multi-disciplinary and across team meetings.

OUTCOMES

Service User Level:

Primary: Primary outcomes are t expected to show improvements earlier in the coordinating intervention. The main aim of the coordinating intervention is to improve the pathway of care so that the health and social care systems, and the third sector function better for the individual and their families. Improving the pathway of care should help to facilitate maintenance and improvements in the health and wellbeing of both individuals living with dementia and their informal caregivers. The intervention aims to improve health related outcome measures including patient quality of life, patient behaviour, patient cognition, patient depression, patient function, caregiver quality of life, caregiver depression and caregiver burden. By involving the service users in dementia care coordination early, it aims to increase the willingness to participate, and improve service user investment in and value of the intervention. Through an increased value in the intervention, it aims to sustain adherence to the care plan.

Intermediate: Intermediate effects will develop throughout the course of the dementia care coordinating intervention. As the intervention aims to strengthen improvements in coordinating care and services, it aims to increase the appropriate use of other resources by service users including care such as; GP appointment times, unplanned hospital admissions, respite care and crisis response teams. By improving the appropriate and timely use of these resources, the intervention aims to reduce the pressure or workload of such resources. Furthermore, it is hoped that improving the functioning of the care system should help improve service users' satisfaction and experience of care, and will hopefully be facilitated by an increased value in the care coordinating intervention.

Long-term: The long-term effects will be seen towards the later stages of dementia care coordination. By improving the coordination of care, the intervention aims to enable individuals to

live in their own homes for as long as is seen appropriate, and when institutionalisation is the most appropriate step, the case manager should facilitate and coordinate the transition into a home to ensure all necessary procedures are complete.

Professional Level:

Primary: Through coordinating services, the intervention aims to help facilitate and improve communication across all sectors of care; health care, social care and third sector services, and aims to fill gaps in care and reduce the potential for duplication of care. By involving a wide variety of professionals and services, dementia care coordination could increase the value and investment placed in the care model. Furthermore, having a clear structure for dementia care coordination and a defined case manager role, the time constraints previously seen in such roles could be reduced.

Intermediate: Throughout the course of care coordinating intervention, it is hoped that health care professionals' satisfaction with care services improves as well as their working environment. By providing early intervention and following a standardised intervention protocol, there should be a reduction in unnecessary use of services and other resources, and avoid ad hoc use of crisis interventions. Furthermore, coordinating care aims to improve the speed of service response in a crisis situation and the general timeliness of service response.

Long-term: In the long-term, the dementia care coordinating intervention could facilitate collaboration across health and social care, and third sector services by improving communication and coordination. This should allow for a more person-centred and holistic approach to care in dementia.

Discussion

Summary of findings

The conceptual model in this chapter outlines a coordinating intervention aimed at individuals living with a diagnosis of dementia and their informal caregivers, and delivered by a qualified nurse based in the CMHT. The model focuses on the planning, facilitating and coordinating care, outlining the proposed resources, intervention components alongside related activities and outputs, and effects of the coordinating intervention in dementia care.

There are a number of required resources for successful implementation including professional partners, care partners and training requirements. There are eight intervention components outlined in a chronological order of how they are likely to occur: participants, identification, comprehensive assessment, planning, responsive, follow-up assessments, evaluation and communication. The model then illustrates activities that are associated with each intervention component and how evidence of these activities can be measured as outputs. Finally, the model sets clear primary, intermediate and long-term outcomes at a service user level and for professionals at a systems level.

Strengths and limitations

The conceptual model is empirically supported by evidence from previous systematic reviews synthesising qualitative and quantitative evidence, found in chapters three and four. As there is no standardised guidance for modelling a complex intervention [148], I made decisions based on the best available evidence. Each component can be related back to evidence from the systematic reviews in chapters three and four, or support from general literature and policy discussed in chapter one, and is therefore justifiable for inclusion. Tables 8, 9 and 10 indicate the mapping process, and the evidence for each aspect of the model. It is important to consider the strength of evidence for each component and section of the model when interpreting the development stage. Due to the small number of trials in the quantitative review (see chapter four) and the lack of information available in trial reports to allow for subgroup analysis, the quantitative

review could only provide evidence and support for a small number of components. This was nursing background and weak evidence for a lower caseload, which is strengthened by the support of the qualitative review findings.

However, there were some components included in the model that were solely based on findings from the review of qualitative evidence which were from the results of five studies. These included some of the postulated outcomes including increasing the value of dementia care coordination with both service users and professionals. These components and sections of the model can be considered to have weaker supportive evidence. However, the following study in my thesis was designed to strengthen the development of the intervention model by allowing critical appraisal and validity from relevant stakeholders.

Furthermore, I was the sole researcher responsible for assembling the model based on the best available evidence. This is an additional limitation in that it could have allowed for researcher biases in the development process. The primary reason for being the sole researcher is rooted in the resource restrictions of the PhD project, in particular time and staff limitations. There are additional processes that could have benefitted the development of the conceptual model such as the inclusion of an expert consensus group to debate the importance and relevance of components of the model. Incorporating views and opinions beyond that of a single researcher could improve the reliability and validity of the development process.

Although the model is in its infancy, it is the first step towards trying to standardise a coordinating intervention for dementia care, where there can be a shared language and vision in how this can be implemented and replicated effectively. However, it is important to recognise that this is the initial stages of intervention development, and can be seen to simplify a complex intervention that will be implemented in a complex setting. Although this is an indication of how things should work, there will likely be a number of interactions between different elements across the model, and may have obvious or unapparent confounding variables. Therefore it is appropriate to approach interpretation with a degree of flexibility.

Conclusion

The conceptual model outlines empirically supported multicomponent intervention for coordinating care for individuals living with dementia and their informal caregivers. By improving the development process and investing in modelling the intervention, it is hoped that research waste is reduced. By providing a clear outline and clear definitions at each stage of the intervention, I aim to improve the potential acceptability with stakeholders at the next stage of development, and improve the chances for successful implementation when moving on to piloting the intervention in a trial.

CHAPTER 6

Service users' and professionals perspectives on current dementia care and views on a conceptual model for coordinating care: a qualitative study

Chapter outline

Following the development of a conceptual model of coordinating care (see chapter five), in this chapter I aim to explore stakeholders' perspectives and experiences of current UK care services under which this model would be implemented, and to investigate the views of the conceptual model. This chapter outlines a qualitative interview study and presents:

- An introductory section to introduce the qualitative work and outline the objectives
- A description of methods used to recruit relevant stakeholders, interview participants and analyse data
- Detailed findings from the qualitative interviews
- Discussion of the methods and findings in reflection of the conceptual model of care and with reference to strengths and limitations, and comparison with existing literature

Introduction

Thus far, my thesis has evaluated the evidence base and developed a conceptual model of coordinating care in dementia following the initial steps of the MRC framework [135]. The MRC framework [135] highlights the importance of using qualitative research methods to provide insight into the process of change in a modelled intervention, and can allow for a wide range of views to be captured and systematically incorporated into the design of an intervention. Qualitative research can also be used to ensure interventions are ready for implementation and to refine the modelling process.

However, following the modelling process and outcomes step in the development phase, the MRC framework [135] suggests moving on to conducting a feasibility trial. Before progressing to the feasibility and piloting phase, I felt it was important to gain more input to the intervention design. This structure follows that outlined by Ettema et al. (2014) [227] who included a 'face validity' stage in developing a complex nursing intervention. In this stage clinical experts including nurses and

surgeons were consulted about the content and clinical application of the intervention. Similarly, I used this qualitative study as an iterative feedback loop to readdress the design of the intervention.

In this study, I wanted to understand more about current care following a diagnosis of dementia, and further investigate the need for coordinating interventions in dementia care and develop a deeper understanding of the context in which the coordinating intervention will sit. I also aimed to integrate this information into the intervention development, and explore the views of stakeholders including individuals diagnosed with dementia, informal caregivers and health and social care professionals on the conceptual model in light of current care settings.

Objectives

The current study aims to use qualitative research methods to explore issues around current care services following a diagnosis of dementia, and stakeholders' views on the conceptual model for coordinating care. There are two specific research questions:

1. What are stakeholder's perspectives and experience of coordination of care services following a diagnosis of dementia?
2. What are stakeholders' views on the likely acceptability, utility and feasibility of the proposed conceptual model of a coordinating intervention for care following a diagnosis of dementia?

Methods

A qualitative approach involving in-depth, semi structured interviews was used. I have followed the COnsolidated criteria for Reporting Qualitative research (COREQ) guidelines to ensure all necessary items have been reported in the chapter (see Appendix 16) [228]. The COREQ guidelines provide an explicit and comprehensive 32-item framework based around three domains: (1) research team and reflexivity, (2) study design and (3) analysis and findings. Further information on methodology can be found in 'rationale for qualitative research' in chapter two.

Participants

Participants were from one of two stakeholder groups; service users and professionals. Participants in the service user group involved individuals who had received a diagnosis of dementia and/or their informal caregivers. Participants in the professional group were individuals who self-identified as having worked within dementia services or care. A maximum variation approach, a form of purposive sampling [229] was used for recruiting both stakeholder groups. This approach aims to create diversity in samples to collect a broad range of information relevant to research questions and identify important common themes.

Service user participants were selected to vary on characteristics such as age, gender and relationship to individual with dementia. There is evidence that male and female caregivers have differing experiences of care giving and its effects [230], and age has also been found as a predictor of caregiver burden [231]. I also wanted to include informal caregivers who varied in their relationship to individual with dementia as there is evidence to show the support given by caregivers and their perceptions of the caring relationship can differ [232]. Professional participants were selected on their background and expertise. I wanted to obtain a range of views from individuals who were in health care, social care and the third sector, and who were at varying career levels. Furthermore, professionals were also selected to vary on sociodemographic characteristic of age and gender, to ensure differences in perspectives and experiences of dementia care could be explored.

Recruitment

I aimed to recruit between 10 to 12 service users, and 10 to 12 professionals. These numbers were based on a study by Guest et al. (2006) [233] investigating saturation in qualitative research who found after coding 12 interviews 92% of the final number of codes had been identified. These recruitment estimates were also based on PhD resources. I was responsible for recruitment and data collection, and therefore numbers were restricted by time and resources. Service user participants were recruited through two main sources; a network of regional community groups including memory cafes and the National Institute for Health Research (NIHR) Join Dementia Research (JDR) database. Local community services including memory cafes have been developing over the last

decade and are most commonly used by individuals living with dementia and their families. Information on Devon memory cafes can be found on the Dementia Roadmap website [234], a resource built to provide detailed information on local services, support groups and care pathways. I had met the majority of participants who were recruited through the memory café prior to participation during multiple visits to memory cafes. The JDR [235] database is a NIHR initiative to encourage and register interest for participating in dementia research. JDR can be used by researchers to identify, screen and contact potential participants matching inclusion criteria.

The professional participants were identified and recruited through existing networks linked with the University of Exeter Medical School, and through personal contacts of myself and the supervisory team. The existing networks at the University refer, but are not limited to professionals who have worked with my colleagues in dementia or mental health research at the University, professionals who have been part of advisory groups or grant applications, and professionals who have previously participated in research at the University. Using existing connections and networks resulted in a form of snowball sampling in which professionals who had been recruited for the study made suggestions of other professionals who may be of interest [236].

Interview tools

An interview strategy and topic guide was developed for both the service user participants and for professional participants (see Appendix 8) to outline the key issues and subtopics to be explored in interviews. Topic guides were based around the two primary research questions. Firstly to explore the broad experiences with the current health, social and voluntary services for dementia, and coordination of these services. Secondly, to investigate views on the acceptability, utility and potential implementation issues relating to the conceptual model.

The semi-structured nature of the interviews allowed for flexibility in the interview process and responses to be open-ended so participants could describe their experiences in their own words [136]. An iterative approach was used in interviews where questions and topic guides could be

modified in reflection of emerging topics. Iteration is a reflexive process that allows the researcher to develop insight and meaning in data that progressively refines the understanding of data [237].

In addition to topic guides, information sheets (see Appendix 9) and a consent form (see Appendix 10) were produced for interviewees. The information sheet outlined the aims of the research, the process of participation and the benefits and potential risks of taking part, and was used to ensure participants were fully informed before agreeing to take part and signing the consent form. This can be problematic when working with individuals with mental health issues and vulnerable older adults. However, I have previous training in informed consent from the University of Exeter Mood Disorders Centre and Good Clinical Practice (GCP) training. The training provides information on policies and guidelines in the ethical and practical elements of gaining informed consent from vulnerable adults and adults who lack capacity. GCP focuses on the rights, safety and well-being of participants and the quality of the research data which is essential to the researchers and project, and covers an overview of the Mental Capacity Act [238]. I also had substantial experience in taking informed consent from vulnerable adults; whilst working on two large scale RCTs I recruited adults who had a clinical diagnosis of depression and/or anxiety.

I did not include individuals who lacked capacity in qualitative interviews because the complexity of questioning around critical appraisal of the conceptual model of care would not have been appropriate. The assessment of capacity was through my communication with the participant, their informal caregiver and the aid from the organisation/route through which they were recruited. If there was any circumstance in which I was unsure if the individual had capacity to provide voluntary, fully informed consent (e.g. due to cognitive impairment) the interview did not take place.

Patient and public involvement

There is a growing evidence base for patient and public involvements (PPI) in health and social care research, much of which indicates a positive impact in aspects such as user-focused research objectives, development of user-friendly study information, surveys and interview

schedules, user focused interpretation of data, improved implementation and user-friendly dissemination of findings [239]. I set out a PPI engagement strategy with two aims:

1. Engage with individuals who are living with dementia, or who have experience of dementia, to further my social interactions in these environments and to gain a good understanding of the dementia community
2. To aid the development of study materials including consent forms, information sheets and other documentation to ensure that it was dementia-friendly and accessible

In order to achieve this, I made 18 visits to eight different memory cafes around Devon before and during the recruitment and data collection stages. In initial visits, I spent time speaking to service users and volunteers at the memory cafes about local dementia services and what they provide, as well as more general discussions around dementia. This process was similar to Savage et al. (2006) [240] who describe a community-based participatory approach where the research team actively participates and partners with community members. This allows an introduction to and learning about the particular community as well as providing access to potential participants. I was able to establish a good rapport with individuals, and gain an understanding of the local dementia community and the network of services available. Becoming known to local groups such as memory cafes was advantageous in the recruitment stage as I had had the opportunity to discuss my PhD project in general, and people showed an interest and willingness to participate.

Following this initial engagement period where I had achieved the first aim of the strategy, I asked individuals who had engaged in conversations over a number of visits if they were willing to discuss and comment on study materials; information sheet, consent form and topic guides. Three discussions took place over three different memory cafes where small groups provided feedback on study materials. In these small groups, individuals were firstly given a brief lay overview of the study and an opportunity to ask any questions. The groups were then shown each of the study materials separately; the consent form, information sheet and topic guide. After allowing groups time to read

each document, discussions took place around issues such as how easy the material was to understand, was there any information missing, was the length of the text appropriate for target population, and the clarity of more complicated issues around consent, confidentiality and right to withdraw. Following this process, study materials were modified and finalised in light of feedback. Individuals that took part in this PPI engagement process were asked to help in this task only, with no expectation of continued input from them within the research project.

Data collection

I approached individuals who attended local memory cafes for recruitment, and screened the JDR database for individuals diagnosed with dementia and informal caregivers. Once potential participants had been identified, they were contacted either by telephone, email or in person, to discuss study participation. Following verbal agreement of participation, a convenient time and location was arranged for the interview to take place, and individuals were sent a copy of an information sheet, a consent form and a copy of the conceptual model (Figures 5, Figure 6 and Box 1). Field notes were taken throughout the process of recruitment and data collection as a tool to reflect on the research process.

The majority of interviews with service user participants were conducted in their homes, with a small number being conducted in a private room at the community location of the memory cafes. All interviews with professional participants were conducted in their place of work. I conducted and audio recorded all interviews face-to-face. I have prior experience in quantitative interviewing using the Structured Clinical Interview for DSM-5 (SCID) to determine clinical disorders in participants and have conducted telephone questionnaires using measures such as the PHQ-9 to screen for presence and severity of depression. I also completed a course in qualitative interview analysis at the University of Oxford that covered elements of qualitative interview techniques.

Prior to the start of the interview participants were given the opportunity to ask questions, and completed a contact information sheet (see Appendix 11) and a case report form to collect

demographic information (see Appendices 12, 13 & 14). Once participants were fully informed of the research, a written consent form was completed.

Ethics

The University of Exeter Medical School Research Ethics Committee granted ethical approval for this study in November 2016 under application number 16/09/104 (see Appendix 15). I have a standard DBS certificate issues in September 2016.

Data analysis

Data were analysed using thematic analysis outlined by Braun and Clark 2006 [156]. Thematic analysis is a foundational and flexible method of qualitative research used to identify thematic patterns within data. Service users' interviews and professionals' interviews were analysed to allow data to be compared and contrasted. Each transcript was coded individually, and throughout the analysis process data was sought for both research question one and two simultaneously; i.e. transcripts were coded chronologically and each line of data were assigned to developing codes, categories and themes of either research question one or two.

Phase 1: Familiarising yourself with your data

This first stage of analysis begins during interviews and transcription, and as part of this initial stage I transcribed all interviews. Bird (2005) [241] argues the importance of transcribing as an interpretive act in the initial analysis process that is key in creating meaning in data, not simply putting spoken words onto paper. Transcripts were then read, re-read and annotated with the noting of initial ideas.

Phase 2: Generating initial codes

Coding of transcripts took an inductive approach and was supported through the use of Nvivo version 11. Each line of the transcript was treated as a separate unit, and each line was assigned one or more codes. Initially these codes were descriptive rather than interpretive in nature, but were not simply a repetition of the words used in the interviews. Line-by-line coding was firstly completed independently by myself and a fellow researcher (AH) on four of the 22 transcripts, two

services user and two professional transcripts. This multiple coder approach allowed for analytic discussion on the coding strategies, and features of the data that were broad and inclusive increasing the validity of analysis [242]. I then independently conducted a line-by-line coding of the remaining 18 transcripts.

Phase 3: Searching for themes

The next stage of analyses involved grouping the line-by-line codes into categories dependent on the similarities and differences each code represented. The groups of categories were repeatedly examined, referring back to the original codes and transcripts, and to ensure the collation of codes formed a pattern and that all data relevant to each category had been gathered.

I took into account the codes from different stakeholder groups, and was aware of differences and similarities in coding between groups. At this stage, the relationship between codes, categories and potential themes was explored. This process continued in an iterative manner.

Phase 4: Reviewing the themes

Categories were then grouped to form subthemes and themes. Firstly, groups of categories were identified to form subthemes, and were repeatedly examined looking at the similarities and differences in their underlying meaning. Some categories were sufficient to form their own subtheme. Interpretive themes were sought to try and identify underlying ideas, patterns and assumptions, and allow for initial descriptive themes to become subthemes to higher level analytic themes in which they were grouped, again dependent on the potential similarities and differences in concepts present in each subtheme.

Subthemes were further grouped to form overarching, analytic themes in a higher level grouping process. The grouping of categories, subthemes and themes was discussed and critiqued in analytic meetings with myself and co-researcher (AH), and input from my supervisory team (CD, DR, RM). Discussing thematic development between researchers is a form of peer debriefing and can improve the trustworthiness of the analysis [156].

Phase 5: Defining and naming the themes

Once the final grouping of themes had occurred, each theme was clearly defined and named to identify and describe the core aspects of each theme and how it fits into the broader context.

Quotes are used to support identified themes. The generic job title and participant ID (e.g. RES001) of each quote is referenced. Some participant IDs are referred to as 'a' and 'b' (e.g. RES001a and RES001b); this is for dyad interviews where both the individual with dementia and their informal caregiver have been interviewed together. Names used in quotes have been changed to pseudonyms.

Quality in qualitative research

There are various ways in which the researcher can impact on the research process and generation of knowledge including the influence of their biases, beliefs and personal experiences [243]. Reflexivity is a reflective strategy used to manage these influences and as a monitoring tool to ensure validity in qualitative research. Bergen (2015) [244] describes reflexivity as the *"process of a continual internal dialogue and critical self-evaluation of researcher's positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcomes"*.

I took numerous steps to enhance the credibility of findings through reflexivity. Firstly, I had prolonged engagement with participants, particularly those recruited from the memory cafes. During my visits to these community groups, and throughout recruitment, and data collection and analysis, field notes were made to reflect on the processes and increase awareness of reactions to engagement, participants and interviews. The contents of these field notes contribute to the 'thick description' of the data [245]. These are discussed in the reflections section of the general discussion. Secondly, multiple coders and peer debriefing [244] amongst coders and supervisors (CD, DR, RM) in thematic development managed researcher bias by including multiple perspectives [246]. These strategies helped me to highlight my own personal perspectives on dementia care, and manage the potential biases.

Results

Participant characteristics

A total of 10 interviews were conducted with service users and 12 interviews with professionals all of whom had provided verbal and written informed consent. One individual living with dementia dropped out at point of meeting for interview as they felt they were unable to contribute to the research having not used any health, social or third sector services following an early diagnosis. A total of six caregivers were interviewed on their own. Two were male with an average age of 67, and four were female with an average age of 72 (see Table 11). A total of four individuals living with dementia were interviewed. At the request of the individuals, all four individuals living with dementia were accompanied by their primary caregiver who actively participated in the interview. Of the four individuals living with dementia, two were male with an average age of 72 and two were female with an average age of 82. Of their accompanying caregivers, two were male with an average age of 80 and two were female with an average age of 68. The mean interview length for caregivers was 44:33 (minutes) and 38:23 (minutes) for dyads of individuals with dementia and their primary caregivers (See Table 12).

The professionals represented a broad range of experiences at various levels of health and social care and the third sector. A total of five third sector workers from a large charity (Alzheimer's Society), three nurses, two psychiatrists, one social worker and one GP were interviewed, with experience in dementia care ranging from 30 years to two years. A total of three male professionals were interviewed with an average age of 41 and nine females with an average age of 45. The mean interview length for professionals was 41:66 (minutes) (see Table 13).

Table 11: A summary of characteristics of informal caregiver participants interviewed on their own

Participant ID	*Interview Length (minutes)*	*Gender*	*Age*	*Relationship*	*Live in*	*Primary Caregiver*	*Hours Caring (day)*	*Marital Status*
RES001	49.14	M	74	Son	Yes	Yes	24	Single
RES002	40.16	F	73	Wife	Yes	Yes	24	Married
RES003	22.57	F	70	Wife	Yes	Yes	24	Married
RES004	56.10	F	73	Wife	Yes	Yes	24	Married
RES007	41.08	M	60	Son	No	Yes	1	Married
RES011	81.35	F	70	Wife & Daughter	Yes	Yes	24	Widowed

Table 12: A summary of individuals with dementia and their informal caregivers interviewed as a dyad

Participant ID	*Individual*	*Interview Length (minutes)*	*Gender*	*Age*	*Diagnosis*	*Diagnosis date*	*Marital Status*
RES005b	With dementia	42.03	M	66	Mixed Dementia: Alzheimer's & vascular	Oct-14	Married
RES006b	With dementia	39.56	F	78	Lewy Bodies & Parkinson's	Jul-13	Married
RES008b	With dementia	33.02	M	77	Mixed Dementia: Alzheimer's & vascular	Jun-12	Married
RES018b	With dementia	38.31	F	86	Alzheimer's	Oct-14	Married

Participant ID	*Individual*	*Interview Length (minutes)*	*Gender*	*Age*	*Relationship*	*Live in/ primary caregiver*	*Marital Status*
RES005a	Informal caregiver	42.03	F	66	Wife	Yes	Married
RES006a	Informal caregiver	39.56	M	74	Husband	Yes	Married
RES008a	Informal caregiver	33.02	F	69	Wife	Yes	Married
RES018a	Informal caregiver	38.31	M	86	Husband	Yes	Married

Table 13: A summary of characteristics of professional participants

Participant ID	*Interview Length (minutes)*	*Age*	*Gender*	*Professional background*	*Job Title*	*Number of Years in Current Role*	*Number of Years Working in Dementia Care*
RES009	25.23	56	F	Nursing	Clinical Team Lead	6 months	30 Years
RES010	52.30	54	F	Nursing	Clinical Team Leader	1 year	30 years
RES012	30.58	40	F	Mental Health Care	Dementia Support Worker	4 Years	20 Years
RES013	40.40	57	F	Health Education Publishing	Dementia Adviser	4 Years	7 Years
RES014	77.37	28	M	Emergency Medicine	Dementia Support Worker	4 Years	4 Years
RES015	45.11	40	M	Psychiatry	Consultant Psychiatrist	12 Years	12 Years
RES016	48.16	35	F	Research	Dementia Navigator	2 Years	2 Years
RES017	34.25	37	F	Care work	Dementia Navigator	1 Year	7 Years
RES019	43.16	39	F	Psychiatry	Consultant Psychiatrist	6 Years	10 Years
RES020	29.45	55	M	Social work	Social Worker AMHP	10 Years	10 Years
RES021	53.50	46	F	Nursing	Community Dementia Matron	5 Years	20 Years
RES022	24.40	40	F	GP	GP	6 Years	15 Years

Results of analysis

There was substantially more data pertaining to the first research question, than the second. This allowed for the creation of more categories, subthemes and themes for question one. During the first phase of line-by-line coding, a total of 425 descriptive codes were developed. These codes were grouped into 65 categories; 50 relating to research question one and 15 to question two. These categories were collated into 18 themes; 15 themes relating to research question one and three relating to question two. The amount and detail of data for question one allowed another level of interpretation, where initial descriptive themes became subthemes to four higher level analytic themes. Table 14 and Table 15 show the themes and categories for both research question one and two respectively. An example of coding can be found in Appendix 17.

The four analytic themes identified pertaining to the perspectives and experiences of current care services following a diagnosis of dementia were; (1) Societal Attitudes, (2) Care Conflict, (3) Disconnected Systems, and (4) Living Well With Dementia. Each of these four themes were comprised of various subthemes discussed below. The three descriptive themes that emerged relating to the views of stakeholders on the conceptual model of care were; (1) Barriers and Facilitators to Model Implementation, (2) Focus of the Intervention and Case Manager Role, and (3) Attributes of Case Manager.

Table 14: Themes, subthemes and categories from analysis for research question one

Theme	*Subthemes*	*Categories*
Societal Attitudes	Ageism	Stigma
		Institutional discrimination
		Lack of understanding
		Generational differences
	Clinical Ethics	Timely quality care
		Accountability
		Respect for autonomy
	Therapeutic Nihilism	No hope of treatment
		Medication
Care Conflict	Pre-diagnosis vs post-diagnosis	Clear diagnosis pathway
		Medication
		Effective acute care
		Cancer comparisons
	Service users as partners in care	Reliance on informal caregivers
		Caregiver support
	Organisational conflict	Tensions
		Professional ownership
	Service user vs. professional experience of care	Continued support
		Making the most of resources
		Under pressure
	Qualified vs. non-qualified workers	Utilising available workforce
		Approach of different workers
		Inclusion of all professionals
Disconnected Systems	Public sector cuts	Fragmented services
		Dependence on funding
		Threshold driven care
		Reminiscence
		Prevention could save money
		Timely care
	Allocation of resources	Overlap in services
		Inappropriate use of services
	Barriers and facilitators to communication and collaborations	Co-location
		Information systems
		Data protection
		Power of referral
		Understanding the purpose of services
	Inconsistency in care	Continued support
		Familiarity
		Outsourcing care
		Turnover of staff
		Postcode lottery
Living well with dementia	Sense of choice	Flexibility of services
		Person-centred care
		Inclusive in decision making
	Loss of personhood	Recovery in older adults and dementia
		Loss of independence and identity
		Dignity
	Social networks	Fear of social isolation
		Peer support
		Sharing information and experiences

Table 15: Themes and categories from analysis for research question two

Theme	*Categories*
Barriers and facilitators to model implementation	Difficulty in funding
	Potential overlap with roles or services
	Concern over caseload
	Integration of the case manager
	Access to information systems
	Support for the case manager
Focus of the intervention and case manager role	Dementia advocate
	Help develop a standardised pathway
	Single point of contact
	Reduce pressure on other resources
	Provision of information
	Health and well-being of service users
Attributes of case manager	Interpersonal skills
	Trade-off between qualifications and costs
	Knowledge of dementia and local services

Research Question 1: What are stakeholders' perspectives and experiences of care services following a diagnosis of dementia?

1. Societal Attitudes

Societal attitudes theme incorporates social belief systems and wider attitudes to dementia and caring for older persons. It includes how society has characterised negative beliefs, feelings and behaviour towards dementia, and how these attitudes are reflected in the current care system and impact on individuals living with dementia. These societal attitudes encompassed three sub-themes: (1A) Ageism, (1B) Clinical ethics and (1C) Therapeutic nihilism.

1A. Ageism

Participants raised the topic of ageism, where individuals living with dementia had felt prejudice because of their age and diagnosis. Service users described a presence of stigma and discrimination in the public, which some felt had caused additional social distress and feelings of embarrassment.

> *'…he says no I don't want to go outside, he didn't want to go out because he didn't want people to see him' Carer & volunteer* (RES011)

Some professionals recognised the stigmatisation of both dementia and older adults, and suggested this was reflected within health care through an institutional discrimination.

> *'And I'm of the view, and I don't think it's completely unreasonable, that if you have dementia, if you're elderly, if you have a mental illness, society generally judges you as less worthy of care, and that there's a kind of institutional discrimination really against people with dementia and mental illness' Psychiatrist* (RES015)

Participants made comparisons with care for younger adults, or other conditions such as cancer, where they felt the care and support was better and did not have as many negative connotations or a 'taboo' label.

> *'With cancer there's no shame behind cancer, there is no taboo behind cancer anymore …. you kind of have the bravery that goes around it; people can get better and get through*

treatment. Whereas with dementia, it's not very nice, and it effects old people, and we don't really like stuff that effects old people because it's a bit weird' Third sector worker (RES014)

The wider attitude of ageism and stigmatisation of individuals with dementia was thought by some to be an indication of the lack of understanding surrounding the condition and mental health in general. Some service users described situations in which they had felt humiliated in public or where tensions had been created within the family or amongst friends following a dementia diagnosis.

'That is the one thing, the problem you have with the family because the family don't understand' Individual living with dementia (RES005b)

'…. people said they lost friends after getting a diagnosis of dementia and I see that, and that's the one thing that probably surprised me when I started this job that people lose friends because of having a diagnosis' Third sector worker (RES014)

Some participants felt the lack of media coverage on dementia or the representation of individuals living with dementia and older adults in the media influenced the public attitudes.

'….because they've done a thing on Emmerdale, I don't watch it but the vicar has dementia and they say do you think it is in the television enough, and I said no' Carer (RES004)

This was mirrored in the discussions around the need to raise public awareness of dementia, and the role of businesses to train customer facing staff.

'And considering how prevalent it is, there needs to be sort of public awareness campaigns about, sort of anyone who works in a public service' Carer (RES008a)

Participants discussed the apparent generational differences in attitudes. Older generations were seen has having traditional views on dementia that portray images of an unknown condition where often individuals were forced into institutions due to a lack of understanding, and there is a sense of shame and embarrassment that comes with a diagnosis of dementia.

'…. we are still dealing with a generation who saw people being out in the old bins for having dementia, as soon as somebody's memory started going or they started exhibiting some sort of strange behaviour everyone knew that strange lady down the end of the road who was a bit weird' Third sector worker (RES014)

'But there is the views the strong held views about dementia being a bad thing, and you know dementia being a shameful thing, and I would say are nearly always found from an older generation' Third sector worker (RES014)

These institutions referred to are the old psychiatric hospitals that were often called 'the bins'. One professional in particular spoke of the difficulty in changing established individual attitudes that reflect societal attitudes of their time.

'So that's very difficult to kind of, and you can't change people's attitudes …. but you can't change deep seated beliefs I've learnt' Third sector worker (RES014)

Furthermore, it was acknowledged that having moved towards recognising dementia as a medical condition and therefore a greater prevalence of diagnoses, we are now dealing with multiple generations living with dementia and holding varying attitudes.

'Especially, I mean don't forget there's two generations within the people that we're dealing with, the common people that we're dealing with. If you're talking about anybody over the age of 65, someone who say is diagnosed at 70 is very different from someone who is diagnosed at 90' Third sector worker (RES014)

1B. Clinical ethics

Many participants, both service users and professionals, talked about the reflection of societal attitudes in the health care system, and discussed ethical issues regarding clinical practice and the care of individuals with dementia and their families. Most service users felt the care and support following a diagnosis was lacking, and to some non-existent, with care that was offered being seen as poor and intermittent. There was agreement among participants around an

individual's right to care and right to receive a certain standard of care that was not currently being provided.

> *'Almost none* [support following a diagnosis] *I would say. We had some pointers for, a booklet or something, with different organisations in. But no direct support I would say, for the dementia' Carer* (RES007)

> *'And erm, I think possibly gave us a few leaflets, and said we'll let you go away and absorb it, sort of thing, because obviously it's err and as I say someone would be in touch with us and we never heard anything again' Carer* (RES003)

> *'Erm, not far off being absent* [support following a diagnosis]*, I think if I'm really honest' Psychiatrist* (RES015)

> *'Nothing, absolutely nothing* [support following a diagnosis]*. I just didn't know what to do' Carer* (RES004)

Some professionals discussed a lack of accountability and responsibility within health care, which was discussed in the context of a lack of care. Participants spoke about the responsibilities of other professions that were not being upheld, and gave examples of circumstances in which they had to chase information, referrals or follow-ups, or situations in which they had to persist with duties that were beyond the boundaries of their given role.

> *'So if we've asked the GP to do something we'd chase it up in a meeting with the GP just to check that it'd been done but yeah other referrals, I'm trying to think. Yes we do chase them up, so we try and you know do what we can within the remit but it's yeah, because you could just spend all your time chasing people' Third sector worker* (RES016)

Service users described a sense of being passed from service to service, feeling disposable and like no one wanted to take on the burden of care.

> *'Yeah, that's right, they set you off …. We weren't misled so much, we just thought that we'd get this girl for a couple of years, but that didn't end up being so' Individual living with dementia* (RES018b)

*'The nurse like, and you must go to your GP which is a rather different kettle of fish *laughs* with the five or six GPs you get down here which ever one you land with may or may not be good at this sort of thing' Carer* (RES018a)

Discussions were had around ethical issues surrounding capacity and the importance of involving both individuals with dementia and informal carers in decisions regarding care. Professionals recognised the importance of this issue, but many service users felt they were overlooked in the decision making process.

'But of course things change, and the carers want to do it different ways, and of course I was saying no we're doing it my way because that's what I've been taught' Carer & volunteer (RES011)

Some participants saw the potential for stigmatisation and discriminating attitudes to hinder service user involvement in care.

'Because I have been to plenty of situations where there is a husband and a wife, one has dementia and one supports them, but neither of them want my support, because of stigma or whatever it might be' Third sector worker (RES014)

1C. Therapeutic nihilism

There was a general sense of hopelessness from both service users and professionals when talking about treatment of dementia. Some service users described a nihilistic attitude from professionals in their approach following a diagnosis, and reported conversations around the fact that there was no treatment or cure for dementia and therefore limited options were available.

'Yes, yes. Well there's nothing we can offer you sort of thing, so go off and enjoy yourself' Carer (RES003)

'And there was no treatment other than the, what he's on, the medications, and the consultant said he's not going to get better but it'll slow down' Carer (RES007)

This was reiterated in professionals reporting a sense of hopelessness and referring to dementia as having no cure or reversible treatment. However, some professionals showed a slightly more optimistic attitude in talking about the medications available to individuals living with dementia and how these may slow the progression of the illness or ease some of the symptoms.

> *'If its medication, we can say maybe you need to try this and do this and see how that goes, and that works, to help with symptoms and such' Clinical team lead & nurse* (RES010)

2. Care Conflict

There was a prevalence of conflict within the care process and systems. The theme referred to conflicts at an individual level among service users and professionals, as well as at a systems level across health care, social care and the third sector. Care conflict incorporates five subthemes; (2A) Pre-diagnosis vs post-diagnosis, (2B) Service users as partners in care, (2C) Organisational conflict, (2D) Service user vs. professional experience of care and (2E) Qualified vs. non-qualified professionals.

2A. Pre-diagnosis vs post-diagnosis

Both service users and professionals perceived a clear divide in their experiences and views on services pre-diagnosis and post-diagnosis, in terms of the process, availability and quality of care. Service users mainly reported positive feedback on the diagnosis process, and described a clear pathway where they felt informed and were in contact with a variety of professionals throughout the course of the diagnosis.

> *'We had this very precise diagnosis; he had lots of tests by the psychologists, and then that was it' Carer* (RES008a)

> *'Yeah, like from the specialist right the way down through to the nurse. It was really good, the whole process from start to finish. The process stretched over nine months just about really, you see various people down through the stages until finally they say right you've got it sort of thing' Carer* (RES018a)

Similarly, professionals described a structured diagnosis route through a system of care, and some professionals were seemingly proud of their involvement in the diagnosis process.

> *'Yeah, for four patients and we had psychology involved, so err a psychologist would do part of the assessment, senior mental health nurse and the consultant, we'd do all the assessment and then we would formulate all the plans. So somebody would get the CT scan and then come in for their assessment and err given a plan' Clinical team lead & nurse* (RES010)

This divide sometimes extended to acute vs chronic care which was emphasized in service users describing a sense of security in the support they were offered if they were on medication. Medication meant there was a requirement for scheduled reviews to assess side-effects, dose, potential changes and other aspects, although there were usually lengthy intervals between reviews.

> *'And I think they do get quite well supported, especially the ones who get started on erm Donepezil or Momentum or something like that, they get the feeling that they're going to be followed up and I don't know how it gets sold, but they get that kind of positive feeling that it's going to be ok' GP* (RES022)

> *'err if somebody's on medication and needs another review, they'll get another review by the community mental health practitioner in about eight weeks following the four week one to see how medication is going' Clinical team lead & nurse* (RES010)

Professionals noted this difference, and some implied an over prescribing culture in health care that could partly be attributed to the limited time for professionals to determine the route of problems.

> *'I fully understand why lots of people are often medicated for things that perhaps don't need medicine because in 8 minutes you can't get to the bottom of the problem' Third sector worker* (RES014)

This was mirrored in wider discussions around acute care. Many service users described experiencing effective acute care when they had an identified health-related problem that needed

addressing, such as a urinary tract infection or a fall. However, once the health-related problem had been fixed individuals were discharged to the community where chronic care appeared to fail them.

> *'I mean they put him in the ambulance and worked on him in the ambulance for quite some time, but they said because of the chest pains they thought it was better to take him in. He stayed in overnight and they did lots of tests on you didn't they? Then I picked you up the next day. But, we couldn't fault them, the treatment he had. Very good' Carer* (RES005a)

> *'Because when people are discharged from err either hospital or day care they go into the community and there's not very much support in the community' Carer & volunteer* (RES011)

Discussions by professionals who reported better funding in acute care reflected this issue, and highlighted difficulties in finding funding for long-term care. One professional highlighted the importance of funding chronic care services to facilitate a reduction in the pressure and the need for acute services.

> *'So I did some work recently and my estimate, and I think it's probably a conservative one, is that in Devon we probably spend about £36 million a year bedding people with dementia in hospital …. And yet looking at the CMHT older people's budget in Devon it's about £7 million a year, and about half of our activity is dementia, so the ironic thing is that 3.5 million, 3.6 million a year trying to make people with dementia better' Psychiatrist* (RES015)

This was followed by a discussion about the need for valid and reliable evidence for long-term interventions. One professional suggested there was sometimes lack in understanding of research and evidence in health care settings like the NHS, and therefore potential to improve those links between research and practice.

> *'Yes, there is a difference between an NHS based process evaluation and a more rigorous research. And there are a lot of people in the NHS who don't understand evidence, and don't understand the basic thing of having a hypothesis and a null hypothesis, and testing it you know through well recognised, vigorous research methodology' Psychiatrist* (RES015)

Many participants, both service users and professionals, drew comparisons with a diagnosis of cancer. There was a consensus that following a diagnosis of cancer there appeared to be a clear pathway regardless of the prognosis.

> *'Yes, and its brilliant the cancer pathway in this country' Third sector worker* (RES014)

> *'You know, when you get a diagnosis of something else, if you get a diagnosis of cancer you're handheld all the way through. Dementia also is a terminal diagnosis but we're not, people are not handheld' Community dementia matron* (RES021)

There were discussions and a general agreement that cancer did not carry the stigma associated with dementia, and that there is a greater public awareness and understanding of the condition.

> *'With cancer there's no shame behind cancer, there is no taboo behind cancer anymore and you know you, everybody knows somebody who has had or been effected by cancer' Third sector worker* (RES014)

Participants also felt cancer services and cancer research received better funding, and that there was more availability of specialists in the condition. This was seen to have helped the development of well-established and high quality cancer services in both acute and chronic care.

> *'Well if you think about the amount of public and private money that goes into cancer research, it needs a similar amount going into dementia research' Individual living with dementia* (RES008b)

2B. Service users as partners in care

Many of the caregivers felt a frustration with services and the lack of support, leading some carers to feel overburdened. There was a heavy reliance on carers to provide 24 hour care to individuals living with dementia. Carers often described being proactive in this role; many spoke about self-directed learning, actively seeking support and chasing follow-ups or referrals.

> *'Then I just started everything I could online, erm you know fortunately I'm quite sassy on the computer you know, and I just looked up and studied everything. And I started going to all*

the support groups, I went to the Alzheimer's Society, I went to Devon Carers, erm and gradually I sort of learnt about who I could contact, and who I couldn't contact' Carer & volunteer (RES011)

Some carers expressed their burden and a resentment of care, reporting feelings of anger and hardship in having the sole responsibility to care for a loved one with little or no support.

'And some days, you see some days I just don't want to look after him. I think, I should be having the life I want. But on the other hand every day he'll say he loves me and it's difficult' Carer (RES004)

They described having a continual worry in looking after someone who is no longer self-sufficient and cannot be left alone, and many carers expressed feelings of burnout.

'Yes, and it actually impacted quite significantly on me, because I felt the need to have little periods of respite during the week and once it got to the stage where I wasn't happy to leave her for 20 minutes to go down into town' Carer (RES001)

'Sometimes I think I don't know if I can carry on, I know I've got to and I know it's not his fault but it's hard sometimes' Carer (RES004)

This was recognised by most professionals, many of whom spoke about the potential for carer burnout and who acknowledge the reliance placed on informal caregivers.

'Carer burnout is the biggest problem for me as GP, and that's the thing that you can see it coming and until the ship crashes we feel fairly impotent about being able to help erm even though you can flag it up' GP (RES022)

Providing inclusive support for informal caregivers and family members of individuals living with dementia was seen by professionals and services as a holistic approach to care. There were many points made about the effects of a diagnosis on family members as well as carers.

'It's reactive rather than erm proactive care, and that's not good enough. Especially as there is always more than one, you know the patients and then there are their family members as well' GP (RES022)

Although most carers felt frustrated and unsupported, many professionals spoke about facilitating care through building good relationships with families and carers.

> *'You see with families, you can do so much if you build a good relationship with families. Because we actually, we work with more with families than we do with the client' Social worker* (RES020)

2C. Organisational conflict

All professionals reported some form of tension between services and organisations in health care, social care and the third sector. Tensions appeared to build between professionals where there was a lack in funding, staff and time, diminishing their ability to provide good quality care.

> *'I think the relationship with social care is really difficult and I think there's a lot of hostility and irritation in health services that social care don't pull their weight and don't do what they need to do, and I think there are tensions around funding' Psychiatrist* (RES019)

Although some professionals saw that they shared a common goal in providing high quality care and maintaining a good quality of life for those living with dementia, they also were aware that they were approaching this goal from very different angles.

> *Q46: 'It's like you think you're doing the best for your patient, they think they're doing the best for their patient, it's very tricky. Yes, we're both trying to get to the same thing we're just coming from very different views on it as well' Clinical team lead & nurse* (RES010)

Social services specifically were described as isolated and seemed to lack meaningful ties with health care and the medical world.

> *'If a best interest meeting is needed from social services, then social services have to, they coordinate that and I think that they struggle because they don't have the links to the people that we might have the links to' Third sector worker* (RES016)

This view was reinforced by service users who reported rarely, if ever, being aware of contact with social services. There was also a lot of tension described between third sector organisations and local community services. In many situations, participants narrowed this back down to funding and a fight for a minimal number of grants.

> *'Erm I don't think that other charities work well together and I think that the main reason for that is because they feel that they are all in competition with each other, which is stupid' Third sector worker* (RES014)

A sense of ownership surrounded some of the discussions of services which seemed to be adding to the apparent conflict. Professionals working for one charity felt in opposition to other charities providing similar services, with some feeling this was an issue around business rather than care.

> *'They might provide some similar services …. we don't necessarily work very well with this charity but their Exeter branch run certain services which I think are invaluable that we don't, thus why would I not refer to those services. There are still people in other charities who think that we are here to steal their stuff or to come and take all their services' Third sector worker* (RES014)

This was also present in health and social care professionals where although there was a sense of pride in a service, there was also a need for control and ownership of the service.

> *'And it ends up getting changed. And I think that because different areas were doing different things prior to setting up the memory matters, they've want to hold on to their own stuff, and it's been a little bit of a err struggle' Clinical team lead & nurse* (RES010)

2D. Service user vs. professional experience of care

Experience of care was the subtheme in which the views of service users and professionals varied most distinctly. Following a diagnosis of dementia, many service users felt unsupported and isolated from the care system. Service users often described little or no contact from health and social care professionals and often turned to peers or local charities for support.

'Erm, but apart from that we didn't get any help with coping with the dementia at all. We had to drive by the seat of our pants. And very gradually we worked our way through erm sort of Devon carers and so on' Carer (RES001)

'No, there wasn't any support at all. I mean, err, I actually, [Matthew] saw the psychiatrist and he had tests, and err I said has he got dementia? And he said yes he has. But then, erm that was it, and I thought oh what do I do now' Carer (RES004)

Additionally, service users conveyed an acceptance in coping with dementia, and a defeatist approach that it was acceptable to be managing and not a necessity or right to have adequate support.

'I don't know what that help is at the moment because I sort of said at that time I felt that I was coping ok …. Just managing, it's just managing everything really' Carer (RES003)

While service users detailed a negative experience of care following a diagnosis, professionals seemed to be more optimistic often describing what services should be and were available. Many professionals spoke about a learning course offered to families following a diagnosis, and also spoke of post-diagnostic meetings between service users and clinicians to offer support. Professionals tended to feel that services were doing the best they could with the limited resources available.

'Erm and the idea is, is that this is a fairly standardised opportunity that everybody gets and erm it usually occurs about a month after the diagnosis is made but clearly there's some variability depending on where and who makes the diagnosis' Psychiatrist (RES019)

However, some professionals described feeling under pressure and constrained. There was a willingness to provide a certain amount or standard of care but an inability to do so because of the boundaries of the service or role.

'So as it stands at the moment, you know, we couldn't do that [keep individual cases open/live for continued care]*. But I know that would be the absolute best thing for the person' Clinical team lead & nurse* (RES009)

Furthermore, some professionals felt a personal responsibility to service users, and reported a difficulty and sadness in dealing with the inevitable progression of dementia.

> *'Unfortunately you do get the bad side of it where if a, the person with dementia that you've probably known for two three years has gone into a care home because they've deteriorated or they've passed away, and that's sad' Third sector worker* (RES012)

2E. Qualified vs. non-qualified professionals

There was substantial debate about the employment of qualified practitioners and non-qualified workers. Some professionals highlighted the importance of matching the skill set of an individual to a role, and recognised a difference in the skills of an individual and their qualifications.

> *'Erm I think the questions for me are about the skills sets of that person and as you say, where they sit' Psychiatrist* (RES019)

One professional raised the issue surrounding applications and employment of clinical jobs being lower than advertised for non-clinical roles. It was seen as a responsibility of the care system to utilise the available skilled workforce.

> *'So what you, what's very apparent is that whenever we advertise a kind of non, a HCA* (health care assistant) *type post or a non-professional type post, or a dementia navigator post in Bristol we're overwhelmed with applications erm so we've got a ready work force we can tap into and we can pay them less' Psychiatrist* (RES015)

There was also a difference described in the approach to care that a trained clinician may have in comparison to a non-qualified worker. Some professionals suggested in a clinical environment, professionals have been trained to identify risks and create actions accordingly. It was suggested that non-qualified workers may have a less medicalised approach to care which could be welcomed by individuals living with dementia and their families.

> *'…. actually if you're from a professional background you see the world a certain way you start to get very quickly into risk assessments and all of this stuff. Whereas if you're not from a professional background, you can go in a bit more light touch, it's more you don't always*

have to ask people how suicidal they are, you don't always have to fill out a ton of statutory sector documentation and you know you can be a bit more human about the whole thing' Psychiatrist (RES015)

This was also apparent in discussions of service users, who felt a non-medical environment was sometimes necessary and could offer some respite from the associations of the medical world and dementia.

'It's comfortable and away from the hospital because we found that people wouldn't go there. They would go there for the clinic, and they would think that they were coming for another clinic' Carer (RES001)

Finally, there was some contention around the status of workers. Some professionals reported having experienced the use of disparaging terms toward non-qualified workers, and the presence of some hostility.

'Because I have heard you know anecdotally in Devon I've heard some members of the community mental health teams occasionally talking in disparaging terms about dementia support workers and what they've said and what they've picked up from a person with dementia, and I think this is not helpful' Psychiatrist (RES015)

Participants had seen a general difficulty in integrating clinically trained with non-clinical professionals, and again had recognised this was an issue of approaching the same goal with differing attitudes and methods. However, it was recognised by both professionals and service users that showing respect for all colleagues was vital and should be done through building trusting working relationships and integrating non-qualified workers into the clinical world.

'Only from the respect point of view that when you're working with all those professionals erm you know, if you don't know what you're talking about then sometimes …. I mean I could go to another area where they sort of think well she's only a volunteer I'm not going to share everything but the people I've worked with, I mean they share with me equally as if I was one of those, as if I was a qualified nurse. And if I don't understand something they will explain it to me' Carer & volunteer (RES011)

3. Disconnected Systems

Many of the participants alluded to a fragmented and disconnected care system that was constructed with isolated hubs of support. Participants debated several potential reasons for a fractured structure of care and how this was affecting the delivery of care. Disconnected systems incorporated four subthemes; (3A) Public sector cuts, (3B) Allocation of resources, (3C) Barriers and facilitators to collaboration and communication and (3D) Inconsistency in care.

3A. Public sector cuts

Many professionals discussed the progression and extent of public sector cuts, and the difficulty this is causing health and social care services. There was a sense that cuts to funding was increasing fragmentation of services, and some professionals talked about the absence of central funding. It was felt by some that having a wide variety of funding sources can be difficult to manage and sometimes cause confusion, also adding to tensions between services that may be fighting for the same finance.

> *'I'm sure everybody you've spoken to will say the same thing, but I think all of the problems and all of the communication difficulties and all of the lack of services whatever it might be is, stems from money and lack there of' Third sector worker* (RES014)

> *'Yes, and I think as well people are often confused, the don't know whether they have to pay for them or if someone else is going to pay for them, they don't know if they can just get on an organise some help coming, or whether they need to wait' Psychiatrist* (RES019)

The cuts and limitations of funding were seen to reduce the abilities of services, affecting the way in which they function and their overall purpose. Both service users and professionals described a reactive care that was threshold driven.

> *'Yes, and thresholds, they have, they are threshold driven rather than erm slightly more pragmatic, if we do something now then it will stop this happening' GP* (RES022)

Professionals had acknowledged and service users had first-hand experience of increasing thresholds where substantial risks had to be present before care and support were granted.

> *'As money becomes tighter, the point of us to intervene gets higher because there is fewer staff the triaging of referrals will mean that only the most risky will be seen' Social worker* (RES020)

This was reinforced by substantial reminiscence running throughout the data. Professionals spoke of the 'old days' when there was less pressure and they felt they had more time to spend with patients who would remain active on caseloads, and more time to communicate with each other including having interdisciplinary meetings.

> *'So I first started working as a CPN nearly 20 years ago, and we done a lot of time with carers and people were on caseload for a long, long period of time. So if people had dementia, we worked with them generally through to the end and then, and also we had a lot of support workers within the community' Clinical team lead & nurse* (RES010)

> *'Yes, I used to go to the interdisciplinary meetings in my old job, I used to attend as a representative of the charity for which I worked, and I was a voluntary sector rep. And they were meetings, it was the physio, the GP, the social worker, the speech and language, and they would have their list of patients' Third sector worker* (RES013)

Service users also talked about a time they felt had passed where they would be able to see their own GP and there would be accessible support in the community such as district nurses.

> *'We would all like to see our GP like we did in the old days, you always saw the same doc and all that lot, but it's not really' Individual living with dementia* (RES018b)

This was echoed by participants' discussions about a need to move from reactive to proactive care, and about the misplaced expense of reactive care and consequences such as unplanned hospital admissions.

> *'So I did some work recently and my estimate, and I think it's probably a conservative one, is that in Devon we probably spend about £36 million a year bedding people with dementia in hospital …. And yet looking at the CMHT older people's budget in Devon it's about £7 million*

a year, and about half of our activity is dementia, so the ironic thing is that 3.5 million, 3.6 million a year trying to make people with dementia better' Psychiatrist (RES015)

Some professionals were in agreement that getting individuals to services sooner would prevent a high risk and would save money in the long run. Both professionals and service users saw value in providing pre-emptive, lower cost care over a sustained period that would avoid a crisis situation, rather than the current situation in which a crisis often needs to be present to initiate a care response.

'Very very much so now and they need to have a substantial risk before they can access services. Where in some ways actually getting people services sooner prevents them from getting to that risk' Clinical team lead & nurse (RES010)

However, despite a 'spend now save later' attitude, it was apparent that there were no funds to inject into preventative schemes to allow them to progress and make those future savings.

'But at the moment, in the current financial climate, getting funds to do double running services is very difficult as well' Psychiatrist (RES015)

Public sector cuts were also seen as a barrier to timely care. Service users reported long waiting times for services including the GP, as well as delays in accessing services and reports of failed follow-up contacts.

'No but she's brilliant our doctor but but you don't, that isn't there. Too many people, I know why it is, but erm its difficult erm to get an, I mean three weeks to get an appointment' Carer (RES004)

This was supported by reports from professionals of the importance of early support in dementia.

'So there's that much more recognition that we need to find people earlier in the dementia to provide them with information and advice about what might happen or what might not happen' Clinical team lead (RES010)

Although there have been government initiatives in improving timely care in dementia, professionals reported not seeing these in action on the front line.

> *'There has been a lot of noise since well since around 2009 really, since the Prime Minister's national dementia strategy and the previous Prime Ministers working parties and what have you on it, but it is a lot of noise and it's in the media and that's all nice but it hasn't really translated into anything meaningful if I'm honest' Psychiatrist* (RES015)

3B. Allocation of resources

With limited and seemingly reducing resources available, many participants spoke about a need for resources to be used more efficiently and effectively. Within the current structure, many professionals spoke of potential overlap in services and roles being offered to individuals with dementia.

> *'You know they could have between two and ten different people going in, and 90% of people wouldn't know what the other ones are doing, we could all be doubling up' Third sector worker* (RES012)

This was echoed by service users who felt they have received similar services, and had previously had to repeat information and sometimes assessments with different professionals.

> *'It's a bit like when you have a problem in the bank or the building society, where each time you phone in you have someone different in the call centre and you have to start all over again with the same thing. And you're screaming to have someone who knows you, who you can get out through to' Carer* (RES001)

The high number of professionals involved in care often caused confusion with service users who sometimes reported being unsure as to who they had seen, why and when they had seen them.

> *'But I've had odd bits of contact with so many folk that it's merging into one in my mind but nothing much ever happens that's of any great use to you' Carer* (RES006a)

> *'No it is, honestly it's like St Pancras, and it's very difficult to know' Carer* (RES011)

The inappropriate or replicated use of resources was also present in reports of unnecessary use of services. Both professionals and service users discussed unnecessary hospital admissions and 'bed blocking'.

> *'So it's really interesting looking at that, so I don't know in Devon perhaps 2% at most of the entire population have dementia and about 30% of your hospital bed your general hospital bed stock is occupied by people with dementia' Psychiatrist* (RES015)

> *'Because he's been taken to Taunton hospital, and it's been dealing with social services in Devon, it's all complicated, we think the best thing is to keep him here until you get back. And just come along when you get back. A bed blocker. They keep on about bed blockers' Carer* (RES002)

Additionally, participants reported inappropriate referrals where professionals had to refuse or pass on a referral because they were not the correct service to address the need. Service users also experienced a cycle of referrals in which they ended up back at the service they had initially contacted without any resolution of the issue.

> *'Oh dear, it's one of these situations where every time the message got passed down the chain it got distorted and it ended up that an appointment came through for the continence clinic which was the door we'd in through in the first place' Carer* (RES006a)

3C. Barriers and facilitators to collaboration and communication

Discussion around collaboration and communication of current services identified potential barriers and facilitators within the current care system. There were elements of the care system infrastructure that appeared to inhibit communication and collaboration, in particular the location of the health and social care staff. Where there was 'co-location', professionals reported an ease of communication, better working relationships and ample opportunity to collaborate and share information appropriately.

> *'We're not integrated, we're co-located, so I sit next to colleagues and that helps share of information, and we do have access to each other's machines because we just sort of say can*

you look this person up for me and tell me what, we do that a lot yeah' Social worker (RES020)

However, where this was not the case, many professionals reported conflict between services and tensions between staff.

'I mean I got a card, when social care moved in to the next building we couldn't get in, we had to go and knock on the door. There's no reception, no door bell, no nothing and you were having to knock on the door. And somebody would come along and go who are you? And I'd go well I'm so and so, this is who I am. Well who are you here to see? Well they're not here. So there was an element you were kept at arm's length' Clinical team lead & nurse (RES010)

Sharing information was not only hindered by a lack of co-location, but also by professionals using different information systems. Professionals reported this often meant information did not reach appropriate individuals or information was being entered into multiple systems, multiple times.

'Yes, we all communicate but if the computer systems don't talk to each other [shrugs]*' Community dementia matron* (RES021)

'And even if those systems are linked, they don't necessarily flag up. So if somebody has gone into hospital and the err later life liaison team see them they have access to our system RIO but it won't flag up, so I will only know about that, that they've gone into hospital, if I happen to be looking on the page' Third sector worker (RES016)

Furthermore, sharing of information was not made any easier by the issues of data protection. Data protection was discussed by both professionals and service users, where professionals found it difficult to share information some service users reported difficulty in obtaining information due to confidentiality.

'….because the doctor is not allowed to contact relatives and say you know it's so hard this confidentiality …. I must come across like that because you know I honestly have had no problems but the carers sort of say you know that, you know I'm not even allowed to go in for the appointment. I mean it's ludicrous' Carer & volunteer (RES011)

The referral process also caused issues with collaboration and communication. In many cases professionals reported strict rules of who had authority over referrals to services, which was often the responsibility of the GP.

> *'Erm it's very frustrating that we can't refer to them and they find that frustrating. It has to go through the GP like everyone has to' Third sector worker* (RES014)

However, in most third sector organisations, referrals tended to be open and came from a variety of sources. Some participants felt the accessibility of open referrals improved communication and awareness of service, particularly with service users.

> *'By anybody, anybody can refer to me, absolutely anybody, and I get referrals from town councils that they're worried about an old lady, erm I get referrals anywhere and I think the fact that it's open, it makes, it makes it accessible' Community dementia matron* (RES021)

There was a lack in understanding of the purpose and boundaries of services, mainly reported by professionals but echoed in service users' confusion of some services and roles.

> *'And people don't understand the difference between the Trusts, they don't understand the difference between health and social care, they don't understand voluntary sector and how that works, they just don't understand it. But how are they supposed to because I can tell you that quite a few health and social care staff struggle with it too' Community dementia matron* (RES021)

Professionals suggested that the uncertainties around the purpose of a service could lead to tensions and be a barrier to communication.

> *'But there might be other people in their GP partnership or within their mental health team who don't understand at all, and that's not surprising because new people come all the time and we know what it's like to learn a new job' Third sector worker* (RES013)

3D. Inconsistency in care

One of the substantial themes around the structure of the care system was the lack of continued support. This was described by many service users as intermittent support or intervals of care. Many professionals recognised this and highlighted the discharge policy of services as a barrier to continued support.

> *'So they're* [Community Psychiatric Nurse's] *pretty good, but yes its limited intervals of care' GP* (RES022)

> *'I think the difficulty that I have, and I know my colleagues have is that we have to discharge people' Clinical team lead & nurse* (RES009)

Both service users and professionals spoke of the importance and necessity of having continued support throughout the progression of dementia, particularly as support will likely need to increase as symptoms advance and individuals move towards later stages of dementia.

> *'When people do reach, more people are in the later stages of dementia and in the later stages of dementia it is very difficult to survive unless you've got 24 hour care and it's certainly enormously difficult for families to deal with' Psychiatrist* (RES015)

Both service users and professionals felt that consistency also encompasses the professionals involved in care. Many participants reported the importance of familiarity. Service users felt a need to be familiar with professionals and discussed the enjoyment of having familiarity with their own GP.

> *'….but to see your GP, which is what older people want, they don't want to be packed off to someone they don't know who doesn't know anything about them, they'll have your whole history and know everything about you, it can take 3 weeks sometimes more than that to see our GP' Carer* (RES008a)

Likewise, professionals reported that familiarity with service users made their job easier. Moreover they felt familiarity with other professionals involved in care made the process smoother.

'And from the other side of that, with my own work I know that err when I do know somebody very well you know it just makes things so much easier to know what's possible and what's not possible' Clinical team lead & nurse (RES009)

The consistency in care was thought to be compromised by outsourcing care to private companies, which is now a common feature in social services. Some service users had experienced companies sending different carers in throughout the day and week, which they found disruptive and sometimes unsettling for the individual with dementia.

'But when [Matthew] got it we had Care South, and they never sent the same person if they sent anybody at all and that upset him you see you've got to have continuity' Carer (RES004)

This also obstructed the need for familiarity. Additionally, there were suggestions that private care companies had more of a business, rather than patient centred, approach to care.

'Erm but the, because what they can afford to pay those private companies has diminished, the market has become distorted really. It's business like really' Psychiatrist (RES015)

The restructuring of services and often high turnover of staff was also seen to prevent consistency in care. Again, this was disruptive for service users and prevented the development of familiarity and therapeutic relationships.

'It could just be a duty social worker or, you know they're changing roles every six months so they might have had Jo Blogs six months ago and now they've got Sam Smith you know, and it's confusing when they haven't got the same social worker' Third sector worker (RES012)

But this was also disruptive for professionals who were relying on building working relationships with staff from other services and sectors, and prevented a good understanding of services and their purpose.

'Does that person have any induction time at all because it's as if she's reinventing it, finding out all this stuff which her colleagues know and her colleagues could tell her, but it seems they don't have time to talk or call, or they don't coincide on the same working days. So that can be frustrating, particularly I think with GPs' Third sector worker (RES013)

On a wider scale, consistency was also lacking in the availability of services from area to area. Many participants described this as a 'postcode lottery' of services, where there was substantial variability in what was accessible, as well as the target group of those services.

> *'There's different things in each area for people with dementia, or for people, you know it doesn't matter whether they've got dementia or not' Community dementia matron* (RES021)

Where some local services seemed to be inclusive of a range of individuals, others were described as exclusive to groups such as those diagnosed with dementia, individuals living alone or individuals in residential homes.

> *'But her support staff interestingly enough said oh it's not dementia oriented, but I've spoken to people here (memory café) who've said oh yeah my wife goes, my husband goes and they're all dementia' Carer* (RES002)

Some professionals saw this as reflecting the lack of a standard underpinning pathway for post-diagnostic dementia care.

> *'Again, I think it is enormously variable, the lack of a standard underpinning pathway mitigates against consistency. So there are some areas where community health, social care, older peoples mental health and primary care all work together very well, and in large part that's less to do with formalised schemes and more to do with just close working relationships on the ground' Psychiatrist* (RES015)

4. Living Well with Dementia

Living Well with Dementia encompasses many issues that were discussed around empowering service users to be more confident in controlling their own life and rights through involving and engaging them in care and supporting them to live a fulfilling and meaningful life. The living well with dementia theme incorporated three subthemes; (4A) Sense of choice, (4B) Loss of personhood and (4C) Social networks.

4A. Sense of choice

Participants felt it was important that patients had a choice in treatment, care and use of services. Many participants, both service users and professionals, spoke of clear preferences individuals showed for certain services and how services can offer various benefits to individuals.

> *'I think it depends on the individual, each individual is different and each person who has the diagnosis is different and their families are different, so their needs are different' Community dementia matron* (RES021)

This was supported by discussion around services being inclusive of users and being flexible in their functioning.

> *'And I'm not saying we haven't got time constraints but we're more flexible with, I'm not going to leave someone if we haven't finished discussing what they need to talk about' Third sector worker* (RES012)

Additionally, many professionals talked about the importance and need for person-centred care which some participants felt included patient choice.

> *'So it's targeting the information we give to what's relevant to that person, it's all very person-centred approach' Third sector worker* (RES012)

Service users felt that having choice in care gave them a sense of control. Being inclusive of individuals with dementia and caregivers in clinical decision making was seen to give service users a sense of choice.

> *'But I was always involved from day one, never had anybody say to me go out of the room. Always involved and that was great, having that choice' Carer & volunteer* (RES011)

One professional suggested that when service users are not involved in decision making, they will rarely question or challenge any decisions made by clinicians.

> *'Families rely on the professionals to help them or to make the decisions to all intents and purposes, there's very few that will say ok well no, she wants this, I want this to happen, this is what's going to happen. They don't challenge very much which is a bit scary really' Community dementia matron* (RES021)

This was mirrored in discussions around authority and how service users will often listen more to clinicians they see in a position of power, such as the GP. These discussions reiterated the importance of person-centred care and the significance of seeing service users as partners in the care process.

> *'Nobody else but the GP certainly, and people have more respect for a doctor than they have for a nurse or for a dementia support worker. That term doctor is very useful' Third sector worker* (RES014)

4B. Loss of personhood

Some professionals spoke about the importance of living well with dementia and individuals living with dementia can feel a loss of personhood. Some professionals suggested spoke of how we can apply the principles of recovery to conditions like dementia, and that recovery is not solely about cure of a condition as sometimes is believed, but is also about the importance of enabling service users to live a fulfilling and meaningful life with a diagnosis of dementia. It was suggested recovery was something that was more heavily applied to curable conditions and to younger populations.

> *'So I guess it's born out of err people with lived experience of mental illness stepping up and talking about how they coped with their mental illness and how they recovered, but the actual definition of recovery is not of cure it's of living a meaningful, fulfilled life along, you know within the sort of limitations of the illness' Social worker* (RES019)

> *'People are still very, very fit and still doing things. Some people are still working people who are self-employed have got, you know carpenters and such who are self-employed are still working at that age' Third sector worker* (RES014)

Service users' discussed issues around a loss of independence and identity which were seen to inhibit living well with dementia. Many service users, particularly carers, spoke about the all-

encompassing diagnosis of dementia and how it becomes the dominant and governing aspect of their life.

> *'We're there, he's sitting there and you're not getting away from dementia at all, it's just your life, I mean it just takes over your life' Carer* (RES004)

For those with a diagnosis there was a conflict between the individual self and dementia, and a struggle to maintain a sense of self while living with dementia.

> *'If someone is depressed or if someone has anxiety those things can be there throughout that person's entire life and then as soon as they get dementia, it's because of the dementia' Third sector worker* (RES014)

Service users and professionals acknowledged the importance of dignity in dementia and care. Some professionals talked about a sense of pride within service users, and maintaining dignity and showing respect are central to providing care.

> *'They're so proud a lot of these people and their dignity and all that, I think talking about it is so upsetting for them, so you have to be really tactful' Third sector worker* (RES017)

4C. Social networks

The significance of social networks for people living with dementia was stated by many participants. Participants spoke of the importance of having a social network and opportunities to develop one. Social isolation was something that service users feared and professionals highlighted as potentially eliciting a deterioration or progression of dementia symptoms.

> *'I'm very conscious of isolation here, erm, well partly myself living on my own. The moment Mother died I took very deliberate steps to get out in the community and get involved …. in terms of NHS funding and so on it's a disaster because they* [older adults who are isolated] *get ill' Carer* (RES001)

The majority of participants discussed in some manner the benefits of peer support. Service users felt the reciprocity among individuals living with dementia and caregivers alike was key in

feeling supported. Many service users had shared experiences and information with others, and spoke of how this had often led to accessing other services.

> *'That's what I've found, if you go into those sorts of things, if people are listening to other people's stories you can say well I dealt with that in this way' Clinical team lead & nurse* (RES010)

This peer support seemed to come from local community services, such as memory cafes, that were provided primarily by third sector organisations.

> *'Because there are some people, I mean I'm, especially since I've been going to things (memory café), I love helping; I pick up strays, I point people all over the place and I actually like it' Carer* (RES004)

Professionals also spoke about the importance of peer support, which was seen as an essential element of care. One professional talked about peer support in relation to providing lived experience groups for dementia, and including people with lived experience in other health and social care services.

> *'But I think there is a lot of value in peer support and I don't think that we offer people with dementia that very well at the moment' Psychiatrist* (RES019)

> *'But I think that there's evidence from other parts of the country that peer support workers with dementia, or peer support workers who have been carers of people with dementia, can actually offer a lot of valuable support to people who are having a diagnosis or looking after others with a diagnosis and erm I think it's, there's some informal peer support when you go to the Memory Matters group, but I think that it is something that's missing' Psychiatrist* (RES019)

Research Question 2: What are stakeholders' views on the proposed conceptual model of a coordinating intervention in dementia care?

Much of the data collected in interviews related to research question one around participants' perspectives and experience of current care services. However, for research question

two participants offered some useful insights into the conceptual model of a coordinating intervention in dementia care. They gave constructive feedback on the proposed model, making some suggestions on improvements and relating aspects of the model back to relevant experience of current services. These are discussed below under three descriptive themes; (1) Barriers and facilitators to model implementation, (2) Focus of intervention and case manager role and (3) Attributes of case manager.

1. Barriers and Facilitators to Model Implementation

All participants engaged in discussions around issues that may hinder or facilitate implementation of the proposed model of care. Funding was a key barrier. Many professionals acknowledged the existing difficulties with funding and debated the potential for case managers to exist within a current structure or the potential to find additional funding.

> *'Costs, yes all this will come at a formidable cost. So, it's thinking about whether these funds come from social services, NHS or some third party. I have no doubt that this kind of system could ultimately result in some cost savings and much improved delivery to end users. And erm, I think it is considering realistic assessment of logistics, costings and potential cost savings' Clinical team lead & nurse* (RES010)

Participants highlighted a potential overlap with existing roles and services. Professionals named a number of roles with which a case manager may overlap, for example dementia support workers, dementia navigators and admiral nurses.

> *'Erm so I guess there is a little bit of overlap with people like perhaps district nurses, Alzheimer's disease people, social care. Everybody's got there little bit of err that support around the person. Erm so there's a little bit of overlap' Clinical team lead & nurse* (RES009)

However, all professionals recognised a current gap in care that could be filled by a case manager; principally the continued support that is offered with the outlined intervention and the specialist knowledge of the case manager.

> *'If somebody, I think it would be much more person-centred and it would be much more useful for all the professionals involved, if there was somebody who, if a best interest*

meeting needed to be brought, that that person could engage all of the different people and be there for continued support' Third sector worker (RES016)

Furthermore, concern was expressed over the case managers' proposed caseload of 1:50. Some service users felt this seemed high considering the scope of the role, while professionals considered this a reasonable but slightly high caseload in light of pressure on current services.

'About the case manager, I was wondering who was going to take these positions on and how many, what enormous caseloads these people would have? If it happens, having a care coordinator you know. It's quite like social workers, they're overwhelmed with the amount of caseloads they have aren't they, as GPs are' Carer (RES008b)

However, some participants suggested this would be manageable considering the stages of individuals on a caseload would vary significantly and therefore so would the time commitments of the case manager.

'I saw it was a ratio of one to 50. So I'm thinking, obviously someone wouldn't just have 50 names given to them, it would be built up over a series of time' Carer (RES003)

There was some discussion around the difficulties in integrating a case manager into existing teams and services. As with many new interventions or restructuring of services, professionals spoke of the initial teething problems that can occur.

'But I think that things eventually get there, it takes a lot of work for everyone to engage, and other teams have to sort of work together to get things up and running' Third sector worker (RES016)

Furthermore, professionals emphasised the importance of giving the case manager authority in various aspects of care including referrals and access to patient records and other care information systems.

'I think that probably is right, as long as there is a clear communication and I think the best way to do that is being able to access systems' GP (RES022)

Having the support of the GP was seen as essential. Participants saw the role of the GP as the original coordinator of care, but reported this was no longer feasible given their pressures and time constraints.

> *'Hmm, erm so I do think the GP is not best place to be err, I think traditionally if you're looking at the complex medical model, yes, I think we do coordinate care quite well, we know our patients well …. But at the same time, in 10 minutes we don't, and the patients with advanced dementia have word finding difficulties, their carers have needs, and a 10 minute consultation can quickly unravel into a 40 minute consultation if you're really going to be doing your job well, and that's just blue sky stuff, that's an ideal world' GP* (RES022)

It was suggested by some professionals that the role of the GP in the intervention should be to give medical input. Therefore, in developing a good relationship with relevant GPs, participants felt the case manager could take up the coordinating role and update and seek guidance where necessary.

> *'…. well you would be having somebody else coordinating it and using the GP as the complex medical opinion, for example when it comes to reducing polypharmacy for these patients and assisting with the medical side of end of life planning' GP* (RES022)

2. Focus of the Intervention and Case Manager Role

All participants saw a value in the model and reported a need for a case manager, expressing that the presented conceptual model would be filling an existing gap in care. There was a consensus that current services and roles lack sufficient time to provide high quality care, and if given that time a case manager could be an advocate for individuals living with dementia, facilitating care and contact with a wider network of services and professionals.

> *'I think if there was a role that was able to* [coordinate care]*, I think that would be really useful as you're almost acting as an advocate as well for that person' Third sector worker* (RES016)

Also, the case manager was seen as having potential to build an architecture or framework around the service user, helping to form the currently lacking standardised pathway of care.

'Someone who can tell you exactly what is around and can be a conduit to all of that. And also if the caseload is not too big, can roughly keep on top of people and risk stratify where they are. So again, at least there's an architecture, at least there is a framework around that person' Psychiatrist (RES015)

Participants saw the case manager as a single point of contact for both service users and professionals who could then facilitate communication between all those involved in care.

'I think it would be quite good erm because we would be able to know who to ask to erm help us, if we made recommendations about treatment or care, we know that we could ask that specific person to do that and they, you know, that might happen' Clinical team lead & nurse (RES009)

Saving patient and clinical time was seen as a key benefit to this aspect of the role, as well as helping with the unpredictable and high workload of other clinicians such as GPs and social workers.

'The service you proposed would indeed be of great value to its end users, it might also help to relieve the somewhat unpredictable load on GPs, social services and others by screening and directing enquiries' Carer (RES001)

As many service users had mentioned the lack of available information on services and on dementia and its symptoms, participants saw the case manager as an opportunity for provision of information. In particular, service users mentioned areas such as legal and financial matters, available local services, what they can provide as well as how and when they could be contacted, and information around their specific diagnosis and progression of the condition.

'I think that again having somebody who, part of their role is to help guide people through the maze of things like housing and benefits and carers allowances and all sorts erm would help GPs with resources and the time pressure' GP (RES022)

'Well it would just be you know what support is available, that we get it. That would be the thing' Individual living with dementia (RES006b)

Many professionals highlighted a benefit of having a case manager would be the presence of a 'link worker' who was responsible for making the connections between the currently fragmented services and plugging service users into the care system.

> *'…the case manager is doing everything, but it is a clearly defined role, you're a link, we're not asking you to do it all, we're just asking you to link up with that other service' Clinical team lead & nurse* (RES010)

One professional saw it as an opportunity to improve the social capital of the local area, by having an individual responsible for improving collaboration and communication between care services and people living in the community.

> *'…. developing the social capital in their area, the area around the GP practices they serve, so just understanding more on what's around, so then they can plug into that community resource and also let the people with dementia and their families know what community resources exist' Psychiatrist* (RES015)

Professionals felt that the case manager could cover some of the ground missing between referral and follow-up, ensuring the care that has been planned is in place.

> *'Because then it could be down to them to ensure that happened, follow that up' Clinical team lead & nurse* (RES009)

In addition, professionals saw the clinical background of the case manager being beneficial in engaging with and advising on care plans of patients and knowing when to follow them up or reassess the plan.

> *'If your case manager is offering a triage role in order to signpost to the relevant service or whether they are, whether you're hoping that they can actually mop up a lot of the issues along the way, if they had a nursing qualification. And I guess the more, with no disrespect, but the more junior, the less skilled the staff the more it is just a triage role and the less they're able to sort of deal with the issues as they arrive' Clinical team lead & nurse* (RES010)

Some professionals suggested the primary focus of the case manager role should be in the health and wellbeing of the patient. With this in mind, many professionals felt the community base of the case manager was important, and an appropriate service would be the Older Peoples Mental Health (OPMH) Teams.

> *'Because you know the emphasis is around mental health and well-being and I think, my view is that should sit within our, the protection of mental health services …. as a manager in the older people's mental health team I could see it working quite nicely with what we do and saying well now it's time to ask for this or you know erm so if it were a part of our team or working alongside our team I think that would be quite good' Clinical team lead & nurse* (RES009)

This was thought to provide a central base between primary care and community services, including social care. Some professionals spoke of clinical supervision, and the opportunity of this within the OPMH team and the chance to review cases within a team that focuses on the health and wellbeing of patients.

> *'I think there needs to be a person with a clinical overview to recognise when it's getting maybe beyond what that person is able to do or the person themselves has questions that their manager can facilitate and know that it's time to come back to the older people's mental health team' Clinical team lead & nurse* (RES010)

3. Attributes of Case Manager

Participants talked about empathy, kindness and understanding as key attributes for case managers in line with the conceptual model. Furthermore, a good judge of character is needed so a rapport and relationship can be established quickly when meeting new people.

> *'Kind I think, and thoughtful. I think you have to be a good judge of character as well to kind of, you're going into situations, you've never met people before, and this is the same for any community services where you're going in blind to something erm and meeting people for the first time, then you have to be a good judge of character and try and judge that quite quickly and know the best way to respond, and the best approach' Third sector worker* (RES017)

The therapeutic relationship was discussed by both service users and professionals, all of whom were in agreement with the models proposal that this should begin early following diagnosis and should be based around trust. The intimate and personal conversations had with individuals following a diagnosis of dementia was seen as a primary reason to establish an early trusting relationship.

> *'Yet you're in there, talking to them about such personal things …. and having really intimate conversations with that couple who were having difficulties within their marriage as a result of this diagnosis, so you're thrown in' Third sector worker* (RES017)

A few discussions around personal attributes also led to conversations based around the qualifications of the case manager which reflected some of the content in the qualified vs. non-qualified workers subtheme in care conflict. Most participants saw a nursing background as an appropriate qualification for the case manager role if they were expected to conduct some clinical duties such as medication management, clinical/physical assessments or providing nursing advice and knowledge.

> *'But some situations they said you'd need to know how to take someone's blood pressure if someone looked like they were unwell. So I suppose that would be good if somebody was trained from a nursing perspective' Third sector worker* (RES017)

This was also seen as a positive in saving time for other clinicians. However, there was also some scepticism: some professionals debated whether the skill set of a nurse was too high if the bulk of the job was triaging, signposting or being a link worker.

> *'Erm, what actual qualification that person, and that team of people would need would be complicated I think. You wouldn't want a highly skilled medical person doing signposting' Carer* (RES007)

But most professionals felt these duties were often central to community nursing, unlike primary care. Additionally, where there are similar existing roles for non-qualified workers they are often paired with clinicians so they are able to draw on clinical skills and knowledge.

> *'We as navigators have practitioners, erm because the practitioners are sort of professional health care, they're usually nurses, mental health nurses, nurses, occupational therapists, physiotherapists, social workers, they've all got that sort of base line qualification …. They're the one's with the most knowledge in the service so they would do that' Third sector worker* (RES016)

A case manager with a nursing background was seen to offer an opportunity to address many problems on the front line of support and not draw on additional resources.

> *'If your case manager is offering a triage role in order to signpost to the relevant service or whether they are, whether you're hoping that they can actually mop up a lot of the issues along the way, if they had a nursing qualification' Clinical team lead & nurse* (RES010)

Participants were in agreement that the knowledge areas of dementia and local community based services were vital for the case manager role. This mirrored the importance of the case manager sitting within the community team, aiding a greater understanding of what is available locally whilst maintaining knowledge of primary care to enable sign-posting and referrals.

> *'They're a caring human being who's had some training, who has access to professionals, who has access to a large national charity, who has access to the NHS, who has access to a GP and also is specifically tasked with keeping in contact with all the people in their caseload in some way, so there is an overview of where people are …. people who are very in need, knocking that up to professional services …. so just understanding more on what's around, so then they can plug into that community resource and also let the people with dementia and their families know what community resources exist' Psychiatrist* (RES015)

Some service users felt it was also important for case managers to submerge themselves within the community, visiting services and communicating with people that might not be on their

caseload. This kind of contact was thought to enhance knowledge and help establish them as advocates in dementia care.

> *'It would be important to come and visit our sessions, that would be good, to meet people and you'll learn more' Carer & volunteer* (RES011)

Discussion

Summary of findings

Both service users and professionals described a fractured system of care that they felt reflected existing discriminatory attitudes around dementia and the care of older adults. Participants felt a sense of hopelessness when it came to the treatment of dementia and a lack of accountability when it came to continued support.

The processes within the current care system appeared to be in conflict. Both stakeholder groups recognised these conflicts across care, but described different experiences of these conflicts. Service users felt isolated and unsupported by the care system, while professionals described the pressures they face and a substantial concern over the funding of care. The structure of the care system was seen to inhibit rather than support collaboration and communication across sectors, which was exaggerated by public sector cuts and inefficient use of resources.

This study also highlights the importance of empowering servic211e users through involving individuals in the care process and clinical decision making. Providing settings where service users were able to create social networks and experience peer support was seen as a positive framework for empowering individuals living with dementia.

Many participants saw the value of having a case manager and felt the conceptual model for coordinating care could be acceptable for individuals living with dementia. Potential barriers to implementation were identified including possible funding issues and overlap with existing services and roles. A nursing background was thought to be suitable for a case manager, but there was some debate around the costs of qualified nurses and the potential to tap into an existing non-qualified

workforce. This reflected some of the discussions in the care conflict theme where trade-offs were considered around the costs of workers and the level of skill required.

Participants saw the focus of the case manager role as being in health care, with case managers acting as an advocate for service users and promoting health and wellbeing. This would be beneficial in helping to empower service users, and facilitate the motion of recovery discussed in the living well with dementia theme. Links can also be seen between the discussion around the potential for case managers to reduce pressure on other resources and improving the distribution of resources that are currently limited, with topics discussed in the allocation of resources and public sector cuts subthemes.

As a link worker, the case manager was thought to be beneficial in acting as a single point of contact for both service users and professionals, and promoting collaboration and communication across care partners. There were clear links here with subthemes in both the care conflict theme and disconnected systems theme. Many of the tensions described in the care conflict theme, such as the organisational conflict and the issues raised with chronic care, as well as the obstructing issues discussed in the disconnected systems theme may be addressed by the case manager role in facilitating communication and collaboration across organisations.

Comparisons with literature

The existence of ageism and discrimination in the care of older adults is well established in the literature. A report by King's Fund (2012) [247] highlights the need to end age discrimination in health and social care, describing discrimination in the form of failure to show respect and dignity in care, and poor accessibility and quality of services for older adults and age-related conditions. Thornicroft (2006) [248] noted that stigma can heighten the distress experienced by those living with dementia, adding to the existing stress of the condition. The findings support the notion that societal attitudes can be discriminatory of dementia and are mirrored in the health and social care system affecting individual's experience of care.

Findings from the study are also coherent with recent reports warning of the fragmented health and social care system that is failing older patients and incapable of managing the complex needs of a growing ageing population [225]. The King's Fund and Nuffield Trust (2016) [249] reported continual cuts to care funding is leaving many older adults without the adequate support or care, and service providers under substantial pressure with constraints on staff, money and time affecting their ability to provide adequate care. This is in agreement with the earlier National Dementia Strategy (2009) [219] that underpinned the need to improve quality of dementia care, emphasising a need to focus on preventing unnecessary crises and improve the quality of life for those living with dementia. Although this strategy was set out, the findings are aligned with recent reports that suggest these plans have not yet translated into practice.

The living well with dementia theme is also consistent with an existing evidence base and has been seen as a core element of person-centred care that promotes patient engagement in health management [250]. The All-Party Parliamentary Group published a report in 2014 [251] on improving quality and sustainability of global health services through patient empowerment. The report suggested several routes to empowerment that echo many themes in the findings; shared decision making, investing in carer support, listening to service users, educating service users and peer support. While these findings reiterate the need to empower service users, there is also literature around the need to empower professionals in dementia care. Beck et al. (1999) [252] discuss empowering nurses to provide high quality care through appropriate training and organisational frameworks, and also reports on barriers to empowering nurses.

Some of the themes found in stakeholders perspectives of current care can be linked to themes found in the qualitative systematic review in chapter three. The review of qualitative evidence focused specifically on stakeholders involved in coordinating interventions in dementia care. Many participants in this study, particularly professionals, highlighted the importance of understanding the purpose of a service or role, and how a lack of understanding can cause difficulties such as inappropriate referrals and miscommunication. This was similar to the review

findings where stakeholders felt clearer definitions and boundaries of role could facilitate communication. A MDT was seen as vital to communication, which was echoed here in professionals expressing a need for MDT and reminiscing about a time in which interdisciplinary meetings once occurred on a regular basis.

Participants described a reactive care system that needs to progress to proactive care. This was also reflected in the qualitative review where the intervention theme highlighted the need for case managers to be more proactive in their role. The therapeutic relationship was discussed in interviews, with participants reporting that consistency in care would facilitate the development of a strong relationship between service users and professionals. This echoed the findings of the review which highlighted the importance of a strong therapeutic relationship.

Finally, participants highlighted the importance of resources, and expressed a concern at the seemingly diminishing resources often as a result of public sector cuts. Resources was a significant theme that emerged from the thematic synthesis and showed that stakeholders were aware of the need for a certain level of resources to implement a coordinating intervention successfully, and issues that can arise when these fall short. Both review and interview findings have discussions around more appropriate use of resources with the potential for services and roles to overlap, which could save time and money.

Strengths and limitations

This study addressed a gap in the current evidence base: adding to a limited body of research in exploring service users and professionals' perspectives and experiences of current UK care following a diagnosis of dementia. It also investigates the views of these stakeholders on an empirically informed conceptual model for coordinating care in dementia. Purposive sampling allowed a range of perspectives from different service users including male and female informal caregivers who were children or spouses of varying ages, as well as individuals with a diagnosis of dementia. A variety of professionals were recruited who had experience in dementia care across a number of settings: health care, social care and third sector services.

A number of strategies were used to help manage potential bias and increase the trustworthiness and quality of this research. Firstly, field notes and some prolonged engagement with participants through memory café visits were used as reflexive processes as a way of attending systematically to the context of knowledge construction and to manage researcher bias. Reflections on the research process can be found in the general discussion in chapter seven. Multiple coders and peer debriefing were used during data analysis to broaden perspectives on data interpretation and increase the validity of findings [253].

Although multiple coders and peer debriefing were used in order to broaden the perspectives on data, I was still responsible for the majority of data analysis. Consequently the research is largely susceptible to biased by my own perceptions. My own reflections on my position as the sole researcher and how I may have influenced the research process are discussed further in the reflections section of chapter seven.

The limitations in time and resources inherent in a PhD project restricted the possible number of interviews that could be conducted, and may have impacted data saturation; ensuring enough interviews are conducted to reach a point where no more new information is emerging relating to the research questions. Although there is evidence to suggest that 10 service user interviews and 12 professional interviews would be sufficient for data saturation [233], this can't be confirmed and failing to reach sufficient data saturation can impact on the quality and validity of the research [254]. I felt that after conducting 22 interviews there was a similar pattern of data arising from both service users and professionals, and there was repetition of experiences with regards to dementia care. There was possibly more room to explore professional stakeholders as the number of individuals from each profession were minimal, a limitation discussed below. However, each individual has a unique perception and therefore, although I believe a good level of saturation was achieved, there is room to gather more data around the research questions posed from a broader and higher number of stakeholders.

Malterud et al. (2015) [255] suggest a new concept of '*information power*' which hypothesises that the more study-relevant information the sample has, the smaller number of participants is needed. Information power will depend on five aspects; (1) study aim, (2) sample specificity, (3) inclusion of established theory, (4) quality of dialogue and (5) analysis strategy. In light of this framework my qualitative study would require a larger sample size for establishing quality and validity. The aim was broad to gain information on experiences and perspectives of current care in dementia, and the sample varied to ensure a range of views were captured. The analysis was data-driven and was not guided by any specific theoretical model. Although the quality of the dialogue was strong with semi-structured interviews using topic guides reviewed by PPI groups, the analysis strategy was cross-case to reveal realistic and pragmatic descriptions of care services.

Furthermore, there were a number of aspects limiting the generalisability of the findings. Although there was a range of participants, the study was conducted in a relatively small geographic location in the Devon region. All of the individuals living with dementia received a diagnosis between 2012 and 2014. Individuals who have lived with the condition longer may have a greater understanding of the changes dementia care has seen over the years. No participants had direct experience of coordinating interventions and all of the professionals interviewed from the third sector were from the Alzheimer's Society. Although one of the caregivers interviewed had volunteered for a number of age and dementia related charities (Hospice, Age UK), the input from the third sector was limited and potentially bias in the views and experiences presented. A range of views from professionals working across the third sector would have been more advantageous because this sector appears to be particularly isolated from health and social care despite providing a substantial amount of local community services.

There was also a number of issues limiting the sample of other professional stakeholders interviewed in the study. Although individuals with a range of professional backgrounds were recruited, there were only one or two from each profession limiting the generalisability of their views to others in the same profession. For example, only one GP was interviewed for the study,

meaning the input and views of GPs were limited. It is possible that using focus groups would have involved more participants and therefore recruited more individuals from each profession.

Service users were recruited from memory cafes and the JDR database. These individuals will be typical of people heavily involved in dementia community activities and groups, and those more willing to take part in research. They may not be representative of those living in the community who are more isolated with the condition. Professionals were recruited through existing networks at the University of Exeter Medical School and personal contacts of the supervisory team, and again may not be representative of those who would not volunteer to participate in research or engage in interviews. However, I have managed to capture the views of those with a wide range of experience of dementia care and current services. The themes emerging from interview data are consistent with current dementia literature, and suggest we can tentatively infer these views are present in the wider dementia community in the UK.

Although analysing the data sets of different stakeholder groups simultaneously allowed for a comparison of similarities and differences in data, it also presented some limitations. In analysing the data sets together with a general grouping of stakeholders to service users' and professionals' could have limited the exploration of different experiences and views of individuals in any depth. This could have had a particular limitation of the exploration of data from professional stakeholders who have different experience in clinical practice and therefore a variety of views on how the model may be implemented in their field of work.

The data was skewed towards research question one. The topic guides were developed to cover topics for both research questions equally. However, participants spent more time talking about current care services and naturally veered back towards their own experiences during questions around the model. This could be due to a number of reasons including the difficulty in critically appraising a theoretical model, particularly for lay participants. When interviewing service users there was a sense of willingness to share their experiences and they were keen to have someone who listened. The interviews were seen as a channel in which they could share their voice.

It may be service users see a researcher as someone in a position of power and a more likely to confirm the model than critique it. Although data from professional stakeholders was still heavily weighted to research question one, they had more critical discussion around the model. This could reflect their knowledge of the care system, how health care interventions work and what is likely to be feasible in current circumstances.

Implications

The findings from this study can be used to further inform the conceptual model for an intervention coordinating care in dementia. The identified gaps and current failing of the care system can be used as targets for the coordinating interventions, and the primary issues raised by stakeholders, including funding, potential overlap of services and role, and caseloads, can be readdressed. The descriptions of a conflicting and disconnected health care system reinforced the need for case managers and the coordination of care. There was a general sense of isolation from service users, so case managers can be used as advocates to support individuals with dementia, to give them a voice in the care system, and to continually plug service users into the care system. Continual cuts left professionals feeling helpless and exacerbated tensions between services and professionals. It is important that the case manager is well established in the health care system and can facilitate communication and collaboration between services and professionals to ease tensions. Having a single point of contact to channel communications should also aid appropriate resource allocation, save time and money in trying to reduce overlap in services and assist with sharing information between stakeholders.

Modifying the model in light of findings will allow future research to move to the following step in the MRC framework [135]; feasibility work to test procedures, estimate recruitment and retention and determine a power safe sample size, followed by a pilot trial. Findings from this study support recent calls for health and social care services to use a collaborative approach that recognises service users as partners in the care process [256]. With reports of a fragmented and confusing care system, findings also reiterate the need to construct a standardised care pathway for

individuals following a diagnosis of dementia that imitates the clear pathways of other conditions [69]. In order to translate priorities, guidelines and policy into action, research investment and funding for care and support needs to increase as dementia still lags behind other conditions such as cancer and heart disease [69].

There is also a need to raise public awareness of dementia and potential behaviours. This should be a focus of companies that have public facing staff and provide custom service to train staff, and help address the issues around stigma. There also needs to be a push to ensure that individuals with dementia are aware of local services available such as the Alzheimer's Society's dementia support workers. There should be a standardised process in which individuals are provided with this information at point of diagnosis.

Beyond the scope of the thesis, research should consider the coordination of services for other chronic conditions, particularly those of a degenerative nature. The treatment and ongoing support of individuals living with chronic illness needs to be tailored to move towards person-centred care, and be responsive to the change in severity and number of symptoms in individuals, with acknowledgement and appropriate measures in place for care of comorbidities.

In the design and evaluation of complex interventions, qualitative research can help explore opportunities for, and barriers to, change, and can identify or quantify components and targets that may be amenable to the intervention [159]. Future research should aim to harness and incorporate the preferences, views and experiences of relevant stakeholders in the early stages of intervention development in the hope it leads to more rigorous, transparent and replicable studies, and more successful implementation.

Conclusion

A significant number of service users and professionals expressed dissatisfaction with the current care system. With reports of fragmentation, tensions and isolation, stakeholders expressed a clear need for change. The connection of services in dementia, and how they communicate and collaborate needs to improve in order to provide high quality care for individuals living with

dementia. There is a clear value in the conceptual model of coordinating care in dementia through the use of case managers, and the intervention is seen to be plugging the current void in links across services.

CHAPTER 7

Discussion

Chapter outline

The discussions of the individual empirical studies in this thesis have been included at the end of each of the relevant chapters, so in this main discussion chapter I present a summary of the thesis so far along with a discussion of the thesis as a whole. Therefore this chapter includes the following sections:

- A summary of the background, aim and objectives of the thesis
- A summary of findings
- The strengths and limitations of the thesis as a whole
- The contributions this thesis makes to the current literature
- The implications of findings for service users, clinicians and the care system, and research
- Reflections on the research process
- Final conclusions

Summary of background

The chronic and progressive nature of dementia results in a unique complexity of care needs for those diagnosed, and it is fast becoming one of the greatest challenges to health care systems across the globe including UK health and social care services. Current dementia care has been described as fragmented and poorly coordinated, offering suboptimum care and poor value for money [62].

To address the short-comings in health care for people with dementia, methods to better coordinate care have been investigated by researchers and health care providers. Such organisational interventions often use case managers to plan, facilitate and coordinate care at varying intensities of involvement, depending on need. These interventions have generally focused on developing a collaborative process of care that aims to provide proactive support for individuals with dementia and their caregivers and families. Research has shown that care coordinating interventions have the potential to improve the health and wellbeing of individuals with a range of

complex health care needs, and can be valued tools in health care services for people with dementia and their informal caregivers [111-114].

However, the evidence for the effectiveness of coordinating interventions in dementia care is mixed. Reasons for the apparent inconsistency of effects seen in previous studies can be attributed, at least in part, to variations in the structure, components, contexts and implementation of these interventions, all of which reflect the diversity and complexity of coordinating interventions and the health care needs of the target population.

This thesis presents a programme of work exploring these variations to understand what components are (i) valued by stakeholders and (ii) important for effectiveness of the interventions. Evidence from prior qualitative studies and trials is then used to underpin the development of a standardised model of care for coordinating interventions in dementia care, which is critiqued and validated through stakeholder interviews.

Thesis aim

To develop a model for a complex intervention to coordinate care for people with dementia.

Thesis objectives

1. To identify key components of coordinating interventions in dementia care for individuals living in the community from the perspectives of varied stakeholders
2. To evaluate the evidence for effectiveness and to identify the extent to which identified key components contribute to the effectiveness of the interventions
3. To develop a conceptual model of an intervention that coordinates care for individuals living with dementia in the community
4. To investigate current experience and perspectives of care coordination among service users and professionals, and obtain views on the likely acceptability, utility and feasibility of a conceptual model of care coordination in dementia

Summary of findings

Systematic review of qualitative evidence

Using systematic methods, I identified five relevant studies providing qualitative data on the perspectives and experiences of stakeholders in coordinating interventions for dementia care. Findings indicated that various groups consider coordinating interventions to be acceptable, useful and appropriate for dementia care, and have clear preferences for components, implementation methods and settings of these interventions. Thematic synthesis [144] identified five broad descriptive themes mapped from 32 codes relating to intervention components that stakeholders felt were important for successful implementation; (1) *Case manager* described preferences for the personal and professional attributes of the case manager, including a sound knowledge of dementia and availability of local services; (2) *Communication* emphasised the importance stakeholders placed on multichannel communication with service users, as well as between multidisciplinary teams and across organisations; (3) *Intervention* focused primarily on the practicalities of implementation such as the contact type and frequency of contacts between case managers and service users, and the importance of case manager training and service evaluation; (4) *Resources* outlined stakeholder views on the required resources for coordinating interventions and potential overlap with existing resources, as well as arising issues when available resources do not meet those required for successful implementation; and (5) *Support* reflected the importance that was placed on the support network around the case manager and the investment of professionals involved directly in care as well as the wider professional network (see Table 4, Chapter 3).

Systematic review with meta-analyses and subgroup analyses

Following systematic searching of electronic databases, 14 RCTs involving 10,372 participants were identified for statistical synthesis. Random-effects meta-analyses and subgroup analyses were used to synthesis data. Results showed that in comparison to care as usual, coordinating interventions reduced caregiver burden (SMD = -0.54; 95%; CI: -1.01 to -0.07; p= 0.02;

n=5, I^2= 92%) and improved patients' behaviours as measured by the NPI (MD = -9.5; 95%; CI: -18.1 to -1.0; p= 0.03; n=4; I^2= 88%).

Trials using case managers with a nursing background compared to trials using case managers from other professions were associated with improved caregiver quality of life (SMD= 0.94 versus 0.03, respectively; p<0.001). Trials that did not provide supervision for case managers were associated with a greater reduction in institutionalisation rates compared with trials that did provide supervision (OR= 0.27 versus 0.96 respectively; p=0.02). There was little evidence of effects on other outcomes, or that other intervention components modify the intervention effects.

Conceptual model of care

Using the Community Tool Box framework [150] the findings from the exploratory sequential reviews, along with general literature and policy, were used to inform the development of a conceptual model for a coordinating intervention in dementia care. The model outlines resources, intervention components and outcomes.

At the heart of the model is the case manager, who is assigned to the individual with dementia at the point of diagnosis and intended to be responsive to the needs of service users. The case manager is responsible for conducting a comprehensive assessment, planning care, conducting follow-up assessments and monitoring progress.

Other key individuals are the GP who remains primary prescriber and is updated on patient's status through communication with the case manager, and a senior member of the CMHT in the supervisory role, responsible for guiding and mentoring the case manager. Also involved are professionals from primary, secondary and tertiary NHS health care teams, social care and third sector organisations. Case managers are responsible for coordinating provision of care from different services, but also for facilitating communication and collaboration across services with a particular focus on a proactive outreach to local community services to include them in the care system.

The model outlines clear primary, intermediate and long-term outcomes detailed at a service user level and at a system level for professionals, including health related outcomes for both individuals with dementia and informal caregivers, along with service users and professionals satisfaction with care.

The qualitative study

Using purposive sampling, I conducted 22 interview with a range of stakeholders; individuals with dementia, informal caregivers, and professionals from health care, social care and third sector organisations. Thematic analysis [156] of interview transcripts identified four analytic themes pertaining to the perspectives and experiences of current care services following a diagnosis of dementia; (1) Societal Attitudes, (2) Care Conflict, (3) Disconnected Systems, and (4) Living Well with Dementia. Both service users and professionals described a fractured system of care that lacked any coherent coordination and reflected discriminatory attitudes thought to be present in wider society. There was recognition of conflicts across care sectors, but different experiences of these conflicts were described, with services users feeling isolated and unsupported by the care system and professionals describing pressures they faced and substantial concern over funding of care. The structure of health and social care, in governance, organisation and provision, appeared to inhibit rather than support communication and collaboration.

Three descriptive themes emerged relating to the views of stakeholders on the conceptual model of care; (1) Barriers and Facilitators to Model Implementation, (2) Focus of the Intervention and Case Manager Role, and (3) Attributes of Case Manager. Overall there was a positive response to the model of care from both service users and professionals, highlighting its potential to address the current need for more coordination in services and a provision of seamless care for those living with dementia. The case manager was seen as potentially beneficial in acting as a single point of contact, which participants considered would facilitate collaboration and communication across care sectors, taking into consideration the views of service users and helping them to navigate the currently fragmented system. However, there were some concerns over elements of the model,

including funding, a potential to overlap with existing roles and services, and the workload of the case manager.

Strengths and limitations of the thesis

Use of robust methodology

The MRC guidance [135] has been used as a framework for the thesis, and the series of studies tackle the consecutive phases of the development stage of the framework: (i) identifying the evidence base, (ii) identifying/ developing theory, and (iii) modifying process and outcomes. This well-established guidance for developing and evaluating complex interventions is flexible in its approach and gives greater focus to the earlier stages of piloting and development work than its earlier edition [159]. Following the MRC framework, the focus throughout the thesis has been on establishing an evidence-based intervention that not only includes evidence from clinical trials, but incorporates all forms of high-quality evidence. This ethos is aligned with the movement of evidence based medicine (EBM), as discussed earlier in chapter two.

The series of studies conducted used robust and reliable methods. The reviewing process systematically and transparently identified, screened, critically appraised and synthesised evidence using rigorous methods of synthesis and were reported in accordance with the PRISMA guidance [169]. The conceptual model was developed using guidance from the Community Tool Box [150] and general guidance from literature available on modelling intervention processes and outcomes. The qualitative study was reviewed and approved by the University of Exeter Medical School Research Ethics Committee (Appendix 15), and was reported in accordance with the COREQ guidance [228]. The study used robust methods for sampling, recruitment, data collection and analysis.

Inclusion of perspectives from a range of stakeholders

One of the key strengths of the thesis is its aim to harness the experiences, perspectives and views of a range of stakeholders on coordinating interventions in dementia care, occurring first in the review of qualitative evidence and then later in the qualitative study. The systematic review reported in chapter three is original in its attempt to systematically capture the views of relevant

stakeholders on coordinating interventions, and investigate their perspectives on valued components of interventions with the intention of using these preferences in intervention development. This was particularly important as the quantitative evidence base was small. Previously, qualitative evidence has been somewhat overlooked in systematic reviews of coordinating interventions. Only two identified systematic reviews, by the same research group, had attempted to incorporate qualitative evidence from relevant stakeholders; one to identify barriers to implementation [116] and one to develop strategies to enhance intervention adoption in primary care [115].

Much of the published qualitative evidence stems from research such as process evaluations embedded within trials. These evaluations can be valuable in offering details on the quality of implementation, potential causal mechanisms and contextual factors impacting intervention outcomes [257]. However, they are somewhat retrospective in nature. This information needs to be harnessed by researchers and used to inform the development and implementation of future coordinating interventions and research, which was the aim of the qualitative review. This has been highlighted as an important pre-implementation phase to secure and consolidate stakeholder support [258]. As debated in the discussion section of chapter four, the purposeful inclusion of stakeholder preferences in trials of coordinating interventions may facilitate more consistent success in implementation and outcomes [148].

There were differences in the topics raised by the service users and professional stakeholder groups. In both the qualitative synthesis and in interviews, professionals had a tendency to focus on the practical elements of care that were tangible, functional and clinical, and highlighted issues around feasibility of intervention components and resources available for implementation. Professionals are in a better position to comment on these elements because of their experience and knowledge of the care system, and their training in practicalities of identifying risk and issuing action points for addressing those in care. Service users on the other hand had a tendency to focus on more personal components that were more conceptual in nature. This included a focus on the

personal attributes of the case manager, highlighting the importance of a good therapeutic relationship and someone to act as an advocate for dementia. Although inclusion of some of these elements might be restricted because of the time constraints of staff, it indicates service users' value of feeling involved in care, having good relationships with professionals and feeling valued as an individual.

Professionals and service users who participated in qualitative interviews differed most notably in the experience of care, which I discussed in detail in the *care conflict* theme. Although both service users and professionals described a fragmented and confusing system of care that provided reactive intervals of care, service users were more pessimistic in their views on current availability and coordination of dementia services, feeling isolated and unsupported. There seemed to be confusion over services they had used, professionals they had seen, and finding and accessing services tended to be by chance rather than through a systematic process or care pathway. Professionals, on the other hand, were more optimistic in their descriptions of the services that were available. Although they showed concerns over limitations in current funding, time and staff, professionals described existing services that should be available to people at point of diagnosis or further down the line. This included a joint initiative between the Older People's Mental Health team and the Alzheimer's Society that provided an opt-in service of a dementia support worker as a single point of contact responsible for signposting, and offering a 'memory matters' course for general education on dementia. Professionals were optimistic about these services and their availability, but there was little discussion of these from service users suggesting there was existing barriers in awareness and accessing of services.

There was a general consensus that involving the informal caregiver in plans for care was important. However, there has been research to suggest that engagement with dementia community services by informal caregivers can have an unintended negative impact on caregiver wellbeing through the stress of 'ambiguous gain' [259]. This concept describes a conflict between the objective goals of services and the subjective experience of caregivers, which can lead to

negative and confusing feelings. It has been hypothesised that engaging with this care system can be intrusive in the caregiver's personal world, exposing the caregiver to additional stressors and experiences of loss of mastery [260]. Consequently, supporting the caregiver and monitoring caregivers' wellbeing is important.

Reliance on the qualitative review

There was a lack of available rigorous qualitative evidence that met the inclusion criteria for perspectives on coordinating interventions in dementia care, which limited the range of views contributing to the findings of the review. Only five studies were identified, and the majority of data came from one feasibility trial [84]. Furthermore, few of the valued intervention components identified in the qualitative studies were assessed in the clinical trials identified, which limited subsequent attempts to establish the effect of identified valued components and led to a heavy reliance on the qualitative review findings in informing the conceptual model.

One possible addition to support the validity of the model would have been to include a consensus group during the development stage. Utilising the knowledge of relevant stakeholders in bridging the gap between the evidence from the systematic review to an intervention that could be implemented in practice could have validated the model. A consensus group could have addressed some of the weaker evidence for the model or some of the more complex issues such as the contradicting evidence around supervision. The potential for a consensus group was discussed in the discussion section of chapter five.

Alternatively, or in addition to, the use of Patient and Public Involvement and Engagement (PPIE) before and during the reviewing stage could have improved the validity and focus of the results. Potential benefits of such involvement can include identification of key outcome measures and improving the quality and relevance of the review to the target population, including, for example, individuals with dementia and clinicians likely to be involved with coordinating interventions. The involvement of PPIE in systematic reviews is discusses further in the discussion section of chapter four.

However, conducting two systematic reviews that included both qualitative and quantitative evidence allowed me to add detail to the model that would not have come out in each review alone.

Order of studies

The purpose of the qualitative study was to cross-check the model with a range of stakeholders to counter balance the issue of relying on the findings from the qualitative review. However, conducting interviews with stakeholders after the development of an initial conceptual model rather than before presented some challenges. There were substantial differences in the amount of data collected for responses to experiences with current care compared to responses related to the conceptual model, and discussions around the model tended to bring about confirmation rather than critique. This could indicate a difficulty in discussing theoretical concepts compared to discussing actual experiences of care. Furthermore, individuals with dementia and informal caregiver may see a researcher as someone in a position of power [261], which might inhibit critical discussion or disagreement with the model.

There is an argument that the sequence of the studies could have included a qualitative study before the development of the model, which may have avoided some of these issues. Additionally, a wider scope could have been taken to incorporate stakeholders in multiple phases from the initial evaluation of evidence, through developing a model of care ensuring appropriate weight was given to the key components, and in critically evaluating the model through iterative discussions and model modifications.

However, the limited time and resources of the PhD project allowed for the completion of only one round of interviews. I decided to use the current available evidence to develop an initial draft of the model to discuss and reflect with stakeholders. The coordinating intervention model is in its infancy, and the development is likely to be an iterative process where this initial draft is refined through multiple stages of discussion and critical appraisal. The findings from the qualitative study can be used in the next iterative phase of development, modifying the model in light of findings from the qualitative study.

There is also an argument around the choice of study design in using interviews for the qualitative work. On reflection, interviews proved difficult in generating data around the model of care. A study design such as focus groups could have been more successful in producing critical discussion around the model and encourage people to scrutinise the model in more detail. Being in a group with other relevant stakeholders with a knowledge of dementia care could have facilitated more content around the model components and potential barriers and facilitators to implementation. This limitation has been discussed further in the discussion section of chapter six.

Contributions to current literature

Contributions of methods

In conducting the studies that comprise my thesis I have incorporated methods from new and developing fields. Methods of synthesis used in systematic reviews have previously favoured quantitative evidence; though there are a number of methods for synthesis of qualitative data, these are relatively new. Mixed studies reviews and attempts to meaningfully combine different forms of evidence is also a new and emerging field, and presents distinct challenges for authors [139]. There is a growing amount of evidence in health services research and increasing levels of complexity within health care interventions, which demands a more comprehensive type of evidence synthesis incorporating different forms and layers of evidence.

The methodology that I used to link the qualitative review findings with the RCTs and subgroup analyses was a novel approach. This was an exploratory, sequential design [139] that allowed an investigation into links between intervention components valued by stakeholders and intervention effects.

There were several barriers that appeared in the process which have been detailed previously. However, the exploratory sequential method in reviewing is a promising approach for future reviews of complex interventions that want to incorporate the views of stakeholders and draw links between qualitative and quantitative evidence.

The MRC framework for developing and evaluating complex interventions [135] outlines an intervention development stage that involves reviewing the evidence base, identifying theory and modelling process and outcomes. However, there are calls for a more comprehensive development stage that includes input from relevant stakeholders who may be recipients of the intervention or responsible for delivering it. Ettema et al. (2014) [227] extended the MRC development stages to include a '*face validity*' phase where a range of experts, including patients and clinicians, are consulted on the content of a novel intervention and its clinical applicability. Bleijenberg et al. (2017) [148] have built on this need and added four elements to the MRC frameworks [135] developmental stage; (1) identifying and defining the problem, (2) determining the needs of recipients and providers of care, (3) examination of current practice and context, and (4) intervention design.

In my thesis I included the additional qualitative interview study to assess face validity of the model, which reflects some of the additional stages suggested by Bleijenberg et al. (2017) [148]; in particular the *'determination of needs'* from the perspectives of recipients of care and providers of care and the *'examination of current practice and context'*. This move towards additional input in the development stage of complex interventions is vital to improve the potential for successful implementation and intervention effects, and help manage and reduce research waste. Furthermore, extending the MRC framework [135] to include these additional stages reflects two of the three pillars of EBM; clinical expertise and the needs and wishes of patients. Designing and testing interventions that are co-produced with knowledge from stakeholders including intended end-users will be more likely to be adhered to, be successful and have an impact in the future.

Contributions to the field of coordinating interventions in dementia

The systematic review of qualitative evidence reported in chapter three demonstrated that there are a number of preferences from a range of stakeholders regarding coordinating interventions in dementia care. This is the first review solely focusing on the synthesis of qualitative evidence in coordinating interventions in dementia care and results can be used to inform future research around preferences and incorporating these in intervention development.

Although the systematic review and meta-analysis was limited in the number of key intervention components that could be evaluated, it provided the first step in establishing a standardised coordinating intervention that is empirically supported, valued by stakeholders and could have potential for successful implementation in dementia care.

The benefits of input from stakeholders during the intervention development stage can help avoid some of the issues identified in implementation science, and discussed in chapter six. Findings from my thesis have established the preferences, and many of the issues highlighted as potential barriers or facilitators have been incorporated in the conceptual model, and therefore with this more tailored intervention it could be possible to overcome some of these implementation issues.

Implications

Service users

The findings presented in this thesis have a number of implications for service users, both individuals living with dementia, and informal caregivers and families of those diagnosed. It supports the notion that following a diagnosis of dementia, care services need to provide more seamless and collaborative care that is good quality and cost-effective. This is vital in supporting individuals with dementia to remain living safely in the community and providing a more person centred approach to care. Coordinating interventions show potential to reduce caregiver burden, which has previously been shown to impact the deterioration of individuals with dementia [32], and may also contribute to improving patient behaviour.

From the qualitative study, there was evidence highlighting the importance of empowerment. Kieffer (1983) [262] conceptualised empowerment in four stages that see it as a process of facilitating individuals to develop autonomy in care decision making. In the entry stage, the experience of dementia threatens the self and family, which Kieffer calls provocation. The advancement stage sees the development of mentorship relationships, with supportive collaborations with family and professionals increasing understanding of the situation and mechanisms for choice follow. The third stage is incorporation and focuses on consciousness and

challenging institutional barriers. Finally, in the commitment stage participants use their new knowledge and skills to empower their day to day lives. The issue around the rights of individuals living with dementia, their autonomy and personhood has largely been ignored until the last 20 years [263]. Findings from the qualitative study interviews add to this body of literature, and reiterate the importance of including service users in decision making, giving them a sense of choice and seeing them as a partner in care and not simply recipient of care.

Goldsmiths (1996) [264] suggests that individuals with a diagnosis of dementia are disempowered by the illness itself and by the way in which others, including family and the general public, react to the illness. This is echoed by findings of ageism, stigma and discrimination discussed in the qualitative interviews. This notion is strongly linked with the recovery movement in psychiatry that describes a personal journey of developing a sense of self, moving towards social inclusion, empowerment and living with meaning [265]. This had traditionally been applied to mental health and younger generations, but there is a more recent push for an inclusion of individuals living with dementia. This has been discussed and researched over the last 30 years, but there is little work about how to best overcome this issue which is where findings from the qualitative study fill this gap. Recovery approaches have reconceptualised professionals as advocates and ambassadors, and the therapeutic relationship as a co-working mutual relationship [266]. If the case manager can mirror this role, coordinating interventions may be able to empower service users to live a fulfilling life with dementia in the true sense of recovery.

Clinicians and the care system

The thesis shows a general consensus that coordinating interventions show a potential for successful implementation in UK settings to improve current care services. The current care system is fragmented, providing reactive intervals of care from a variety of professionals and services. Coordinating interventions do not fit within a single organisation or profession because of the emphasis on collaborative working across the system. Developing and implementing evidence-based initiatives that foster greater collaborative working are required, and findings from this thesis

suggest the use of case managers are likely to be able to facilitate a care system that provides more collaborative, seamless care for individuals with dementia.

There are existing programmes within health care services that make recommendations for the use of case managers [262, 263], but the process, nature and organisation of such programmes. This research has addressed the limitations of previous research by exploring coordinating interventions in more depth and trying to tease apart what are considered the key components. Restructuring such programmes and embedding identified key components from this research could be achievable as service models have the capacity to evolve.

Findings from both the review of qualitative evidence and the stakeholder interviews support the notion that a case manager in a coordinating role would be useful in alleviating some of the pressures on other services, particularly in primary care. Findings from the qualitative work highlighted the issues with current use of medical models where the GP lies as the first port of call for patients. This has led to GP time being used for appointments that could be more suitable elsewhere, saving both GP appointment time and additional administration time.

Although the value of coordinating interventions was evident, findings still reveal underlying concerns over the applicability of such models of care for mental health and dementia, and the feasibility of implementing some of the higher-order organisational changes within a well-established system such as the NHS. These questions could be addressed in future work around coordinating interventions in dementia, in particular feasibility work followed by a fully powered RCT, which is discussed in the next section of the discussion.

Given the current economic climate in the UK, the NHS is under considerable stress. As we've seen throughout the thesis, the stretch of funding, staff and resources is already significant and it is hard to consider the implementation of a new intervention without clear evidence of cost-effectiveness. Although recommendations of case managers exist within current UK guidelines for chronic disease management [267, 268], there is no indication that coordination occurs on a consistent, evidence based or regulated manner using any standardised models of care.

Consideration should be taken over the use of existing resources such as district nurses, community psychiatric nurses or community matrons to implement an empirically informed, standardised coordinating intervention. Although this would require restructuring of services or redefining of roles, it could help address the distribution of resources and utilisation of the current NHS workforce.

Furthermore, as we saw in chapter one, the majority of care for individuals with dementia takes place in the community. Although individuals with dementia have a higher risk of unplanned hospital admissions and longer stays once admitted [63, 64], the findings of the thesis indicated a more positive experience in acute care settings than with community care. This suggests a need for funding and provision of community care in the UK to increase not only to improve the experience of care for service users, but to also help reduce the pressure and unnecessary use of NHS acute services in crisis. The majority of care also falls on the family and caregivers of the individual diagnosed, which can lead to caregiver burden as outlined in chapter one. We have seen an effect of coordinating interventions in reducing caregiver burden. This reiterates the importance for care services and professionals to take a holistic approach to care that is inclusive of caregivers and address their needs as much as the individual diagnosed.

Future research

There is a lack of robust evidence on the effectiveness of coordinating interventions in dementia care or of the association of components with intervention effects. Funders should therefore invest in research that aims to comprehensively include stakeholder preferences during development and implementation of coordinating interventions. Measures of these preferences should be included in trials to evaluate associations with effect. Furthermore, the delivery of coordinating interventions needs to be evaluated for fidelity to the delivery plans. As well as the lack of clarity in reporting complex interventions, some trials of coordinating interventions have found that case managers were not working to the intervention protocol [124]. Improving the adherence to care processes could improve the quality of care and effect on outcome measures.

In moving this research forward, the next stage would be to make modifications to the coordinating intervention in light of findings from the qualitative study. This would provide the opportunity for issues raised with the current model, namely funding, potential overlap in services and roles and case manager caseload, to be readdressed.

Further research using focus groups of service users and professionals may be a useful tool in generating more critical discussion around the model of care, and its likely acceptability, utility and feasibility in current UK care settings. Focus groups could provide a supportive environment where participants feel comfortable to critique, and working in groups could facilitate discussion and challenges to the model. We saw the importance of peer support earlier in the chapter six, and allowing an environment for individuals to share experiences may also unveil important information for coordinating interventions in dementia care [269].

Following the incorporation of feedback into the conceptual model, the next stage would be feasibility work and a pilot trial. Feasibility work would be completed in order to address the question of 'can it be done?', and involves reviewing the uncertain parameters of an intervention and describing methods for improving their precision [270]. A feasibility study for the coordinating intervention will involve developing training materials to facilitate the training of a nurse to act as a case manager as described in the conceptual model. Following training, case managers will be responsible for delivering the coordinating intervention over a set period of time to a limited number of individuals with dementia and informal caregivers. Data will be collected on the implementation and procedures of delivery, as well as how easy it is to recruit and retain individuals with dementia and informal caregivers. Qualitative data can be collected from a range of stakeholders involved to explore the feasibility, views on barriers and how these can be overcome, views on facilitating factors and how these can be incorporated, as well as whether additional modifications need to be made.

Once a feasibility study has been completed, and modifications and refinements have been made, a pilot study can be conducted. A pilot study is a smaller version of a full scale trial to test

whether the components and processes of the main study can work together [270]. Again, this will involve training identified nurses as case managers, using training materials potentially modified in light of feedback. A small sample of individuals with dementia and informal caregivers will be recruited and randomised to either the intervention group or likely treatment as usual. Data will be collected on the key outcome measures as outlined by the model to estimates intervention effect, including an estimate of cost-effectiveness, and standard deviations can be used to power a subsequent full trial. A process evaluation will also collect measures on feasibility and acceptability of trial processes. Following promising results from a piloting stage, the research would progress to a fully powered RCT over multiple centres to establish clinical and cost-effectiveness.

For future research in general, the findings of my thesis have highlighted some important critiques. First, the standards of reporting within research needs to be addressed as this can be a barrier to synthesis in systematic reviews. Improving standards of reporting could also help enhance the rigour, transparency and replicability of studies, and can allow for interventions, such as those coordinating care through case managers, to be fully evaluated and improved. Furthermore, the field of complex interventions should enhance guidelines on intervention development stages and begin to extend the MRC framework for further inclusion of stakeholders as suggested by Ettema et al. (2014) [227] and Bleijenberg et al. (2017) [148].

Reflections

It is important to reflect on the research process, particularly where qualitative research methods are employed. I was fortunate to have shared some of the experience with fellow PenCLAHRC PhD students in a *Dementia Community of Practice* group. The community of practice was set up as a peer support group for students researching around the topic of dementia, and as a forum for collective learning in health services research. This has been both a supportive structure throughout the course of the PhD, and a useful resource for practical elements of the project including access to second reviewers, proof reading and shared learning and training. Communities of practice are a relatively new concept but have been recommended as a reflexive practice of the

research process [271]. Reflexivity is stimulated through discussions about our own research projects, drawing on similarities and differences in findings and experiences, as well as wider discussions around dementia and research.

It was also important to reflect on my own position within the research, as both researcher and participants will impact on the research process. I had previously gained some experience of working with individuals diagnosed with dementia as a community support worker, and had knowledge of the topic from a prior research project with Health Education England in developing criteria in dementia education. However, the exposure and engagement levels of my PhD far outweighed any of my previous experience. As a younger adult researching dementia, I was engaging with many participants who were of different generations and I became increasingly aware of some of the issues emerging around ageism, stigma and discrimination. I hadn't been consciously aware of the prevalence of these larger social issues prior to engaging with local dementia groups and the initial stages of the qualitative interviews. This could have affected the way in which I engaged with individuals with dementia and informal caregivers, perhaps in comparison to engagement with professionals.

Reflecting on some of the field notes I made during prolonged engagement with stakeholders and visits to community dementia groups, there was an existing dejected tone in informal conversations with service users. On my first visit to a memory café, during conversations with volunteers about care services for dementia and how they were coordinated, a volunteer had used the term 'fragmented' and 'left hand doesn't belong to the right'. This seemed to set the tone for much of the data that came from the following interviews with service users when discussing the current care system.

It is important to remain mindful of how my positionality influences the research process, and communicating positionality and being transparent with participants regarding research intent should be efforts for future research. While I hope that the findings of my project contribute to the

field of dementia care and coordinating interventions, further lessons have come from the research experience itself.

Final Conclusions

There is a need to move towards a standardised model for coordinating interventions that harnesses the preferences of stakeholders responsible for delivering care, and those who are living with a chronic condition such as dementia. Developing such a model could improve the transparency, evaluation and replicability of coordinating interventions, and thus move towards more consistent and successful implementation to improve the lives of those living with dementia.

My thesis has presented a body of work that contributes to the current knowledge around coordinating interventions in dementia care. The work has identified a range of intervention components, implementation methods and settings which stakeholders prefer. Some of these identified have been proven to have associations with intervention effects. Incorporating these preferences into a conceptual model of care had a positive response with both services users and professionals seeing the model as a valuable tool in coordinating dementia care, and a process that could fill a current gap in a fragmented care system.

APPENDICES

Appendix 1: Master Search Strategy in MEDLINE (OvidSP)

Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present>

Search Strategy:

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1 exp Dementia/

2 dement*.mp.

3 alzheimer*.mp.

4 (presenile/ or senile.mp.) and dement*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]

5 *Delirium, Dementia, Amnestic, Cognitive Disorders/

6 *cognition disorders/ or *mild cognitive impairment/

7 1 or 2 or 3 or 4 or 5 or 6

8 Case Management/

9 collaborative care.mp.

10 case manag*.ti,ab.

11 care manag*.ti,ab.

12 (care adj2 coordinat*).ti,ab.

13 (case adj2 coordinat*).ti,ab.

14 service coordinat*.ti,ab.

15 care consult*.ti,ab.

16 case consult*.ti,ab.

17 (care adj2 facilitat*).ti,ab.

18 shared care.ti,ab.

19 (coordinat* adj2 care).ti,ab.

20 admiral nursing.mp.

21 *disease management/

22 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 (33785)

23 7 and 22

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[mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]

[ti,ab= title & abstract]

Appendix 2: 10 questions of the CASP quality appraisal tool for included studies in the qualitative systematic review

Study ID (author date)	Gladman 2007	Iliffe 2014	Kosteniuk 2014	Minkman 2009	Van Mierlo 2014
1. Was there a clear statement of the aims of the research? (Y/ Can't tell/ N)	Y	Y	Y	Y	Y
2. Is a qualitative methodology appropriate? (Y/ Can't tell/ N)	Y	Y	Y	Y	Y
3. Was the research design appropriate to address the aims of the research? (Y/ Can't tell/ N)	Y	Y	Y	Y	Y
4. Was the recruitment strategy appropriate to the aims of the research? (Y/Can't tell/ N)	Can't tell	Y	Y	Y	Y
5. Was the data collected in a way that addressed the	Y	Y	Y	Y	Y

research issue? (Y/ Can't tell/ N)					
6. Has the relationship between the researcher and participants been adequately considered? (Y/ Can't tell/ N)	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell
7. Have ethical issues been taken into consideration? (Y/ Can't tell/ N)	Y	Y	Y	Can't tell	Y
8. Was the analysis sufficiently rigorous? (Y/ Can't tell/ N)	Y	Y	Can't tell	Can't tell	Y
9. Is there a clear statement of findings? (Y/ Can't tell/ N)	Y	Y	Y	Y	Y
10. How valuable is the research?	A valuable service evaluation assessing quality of care and conditions of care, which will be useful for replication of service.	Adds substantial value in trying to replicate a US trial in the UK, and contributes valuable, detailed findings from process evaluation.	Research contributes valuable findings from GPs views on coordinating interventions, but is lacking in detail and confined to rural settings.	Research is valuable in comparing variations of case management programmes, but needs more detail in findings.	Provides useful and novel insight into the barriers and facilitators to delivering coordinating interventions.

Appendix 3: Studies included in the systematic review with meta-analysis and subgroup analysis, and all associated papers

Study ID	*Associated papers used in the review*
Bass 2003	Bass DM, Clark PA, Looman WJ, McCarthy CA, Eckert S. The Cleveland Alzheimer's Managed Care Demonstration: outcomes after 12 months of implementation. The Gerontologist. 2003;43(1): 73-85. Clark PA, Bass DM, Looman WJ, McCarthy CA, Eckert S. Outcomes for patients with dementia from the Cleveland Alzheimer's managed care demonstration. Aging & Mental Health. 2004;8(1): 40-51.
Bass 2014	Bass DM, Judge KS, Snow AL, Wilson NL, Morgan RO, Maslow K, Randazzo R, Moye JA, Odenheimer GL, Archambault E, Elbein R, Pirraglia P, Teasdale TA, McCarthy CA, Looman WJ, Kunik ME. A controlled trial of Partners in Dementia Care: veteran outcomes after six and twelve months. Alzheimer's Research & Therapy. 2014;6(9): DOI: 10.1186/alzrt242 Judge KS, Bass DM, Snow AL, Wilson NL, Morgan R, Looman WJ, McCarthy C, Kunik ME. Partners in Dementia Care: a care coordination intervention for individuals with dementia and their families. The Gerontologist. 2011;51(2): 261-272. Shrestha S, Judge KS, Wilson NL, Moye JA, Snow AL, Kunik ME. Utilization of legal and financial services of Partners in Dementia Care study. American Journal of Alzheimer's Disease and Other Dementias. 2011;26(2): 115-120.

	Bass DM, Judge KS, Snow AL, Wilson NL, Looman WJ, McCarthy C, Morgan R, Ablorh-Odjidja C, Kunik ME. Negative caregiving effects among caregivers of veterans with dementia. American Journal of Geriatric Psychiatry. 2012;20(3): 239-247. Bass DM, Judge KS, Snow AL, Wilson NL, Morgan R, Looman WJ, McCarthy CA, Maslow K, Moye JA, Randazzo R, Garcia-Maldonado M, Elbein R, Odenheimer G, Kunik ME. Caregiver outcomes of Partners in Dementia Care: effect of a care coordination program for veterans with dementia and their family members and friends. American Journal of Geriatric Psychiatry. 2013;61: 1377-1386. Morgan R, Bass DM, Judge KS, Liu CF, Wilson N, Snow AL, Pirraglia P, Garcia-Maldonado M, Raia P, Fouladi NN, Kunik ME. A break-even analysis for dementia care coodrination: Partners in Dementia Care. Journal of General Internal Medicine. 2015;30(6): 804-809.
Callahan 2006	Callahan CM, Boustani MA, Frederick FW, Austrom GM, Damush TM, Perkins AJ, Fultz BA, Hui SL, Counsell SR, Hendrie HC. Effectiveness of collaborative care for older adults with Alzheimer's disease in primary care: a randomised controlled trial. The Journal of the American Medical Association. 2006;295(18): 2148-2157. Guerriero-Austrom M, Damush TM, Hartwell CW, Perkins T, Unverzagt F, Boustani M, Hendrie HC, Callahan CM. Development and implementation of nonpharmacological protocols for the management of patients with Alzheimer's disease and their families in a multiracial primary care setting. The Gerontologist. 2004;44(4): 548-553.
Chien 2008	Chien WT, Lee YM. A disease management program for families of persons in Hong Kong with dementia. Psychiatric Services. 2008;59(4): 433-436.
Chien 2011	Chien WT, Lee IY. Randomised controlled trial of a dementia care programme for families of home-resided older people with dementia. Journal of Advanced Nursing. 2011;67(4): 774-787.
Chu 2000	Chu P, Edwards J, Levin R, Thompson J. The use of clinical case management for early stage Alzheimer's patients and their families. The American Journal of Alzheimer's Disease and Other Dementia. 2000;15(5): 284-290.
Dias 2008	Dias A, Dewey ME, D'Souza J, Dhume R, Motghare DD, Shaji KS, Menon R, Prince M, Patel V. The effectiveness of a home care programme for supporting caregivers of persons with dementia in developing countries: a randomised controlled trial from Goa, India. PLoS One. 2008;4(6): e2333.
Eloniemi-Sulkava 2001	Eloniemi-Sulkava U, Notkola IL, Hentinen M, Kivela SL, Sivenius J, Sulkava R. Effects of supporting community-living demented patients and their caregivers: a randomised trial. Journal of the American Geriatrics Society. 2001;49: 1282-1287.

Eloniemi-Sulkava 2009	Eloniemi-Sulkava U, Saarenheimo M, Laakonen ML, Pietila M, Savikko N, Kautiainen H, Tilvis RS, Pitkala KH. Family care as collaboration: effectiveness of a multicomponent support program for elderly couples with dementia. Randomised controlled intervention study. Journal of the American Geriatrics Society. 2009;57: 2200-2208.
Jansen 2011	Jansen APD, van Hout HPJ, Nijpels G, Rijmen F, Droes RM, Pot AM, Schellevis FG, Stalman WAB, van Marwijk HWJ. Effectiveness of case management among older dults with early symptoms of dementia and their primary informal caregivers: a randomised clinical trial. Internaitonal Journal of Nursing Studies. 2011;48: 933-943.
Lam 2009	Lam CW, Lee JSW, Chung JCC, Lau A, Woo J, Kwok TCY. A randomised controlled trial to examine the effectiveness of case management model for community dwelling older persons with mild dementia in Hong Kong. International Journal of Geriatric Psychiatry. 2010;25: 395-402. Kwok T, Lam L, Chung J. Case management to improve quality of life of older people with early dementia and to reduce caregiver durden. Hong Kong Medical Journal. 2012;18(6): s4-6.
Newcomer 1999	Newcomer R, Miller R, Clay T, Fox P. Effects of the Medicare Alzheimer's Disease Demonstration on Medicare expenditures. Health Care Financing Review. 1999;20(4): 45-65. Yordi C, DuNah R, Bostrom A, Fox P, Wilkinson A, Newcomer R. Caregiver supports: outcomes from the Medicare Alzheimer's disease demonstration. Health Care Financing Reviw. 1997;19(2): 97-117. Arnsberger P, Fox P, Zhang X. Case manager-defined roles in the Medicare Alzheimer's disease demonstration: relationship to client and caregiver outcomes. The Care Management Journals. 1999;1(1): 30-37. Miller R, Newcomer R, Fox P. Effects of the Medicare Alzheimer's disease demonstration on nursing home entry. Health Service Research. 1999;34(3): 691-714. Newcomer R, Spitalny M, Fox P, Yordi C. Effects of the Medicare Alzheimer's disease demonstration on the use of community-based services. Health Services Research. 1999;34(3): 645-667. Newcomer R, Yordi C, DuNah R, Wilkinson A. Effects of the Medicare Alzheimer's disease demonstration on caregiver burden and depression. Health Services Research. 1999;34(3): 669-689. Fox P, Newcomer R, Yordi C, Arnsberger P. Lessons learned from the Medicare Alzheimer disease demonstrations. Alzheimer Disease and Associated Disorders. 2000;14(2): 87-93. Gaugler JE, Kane RL, Kane RA, Newcomer R. Early community-based service utilization and its effects on institutionalisation in dementia caregiving. The Gerontologist. 2005;45(2): 177-185.

Samus 2014	Samus QM, Johnston D, Black BS, Hess E, Lyman C, Vavilikolanu A, Pollutra J, Leoutsakos JM, Gitlin LN, Rabins PV, Lyketsos CG. A multidimensional home-based care coordination intervention for elders with memory disorders: the maximising independence at home (MIND) pilot randomised trial. American Journal of Geriatric Psychiatry. 2014;22(4): 398-414. Tanner JA, Black BS, Johnston D, Hess E, Leoutsakos JM, Gitlin LN, Rabins PV, Lyketsos CG, Samus QM. A randomiszed controlled trial of a community-based intervention: effects of MIND at home on caregiver outcomes. American Journal of Geriatric Psychiatry. 2015;23(4): 391-402.
Vickrey 2006	Vickrey BG, Mittman BS, Connor KI, Pearson ML, Della Penna RD, Ganiats TG, Demonte RW, Chodosh J, Cui X, Vassar S, Duan N, Lee M. The effect of a disease management intervention on quality and outcome of dementia care: a randomised trial. Annals of Internal Medicine. 2006;145(10): 713-726. Chodosh J, Berry E, Lee M, Connor K, DeMonte R, Ganiats T, Heikoff L, Rubenstein L, Mittlman B, Vickrey B. Effect of a dementia care management intervention on primary care provider knowledgem attitudes and perceptions of quality of care. American Journal of Geriatric Psychiatry. 2006;54(2): 311-317. Duru KO, Ettner SL, Vassar SD, Chodosh J, Vickrey B. Cost evaluation of a coordinated care management intervention for dementia. The American Journal of Managed Care. 2009;15(8): 521-528. Chodosh J, Pearson ML, Connor KI, Vassar SD, Kaisey M, Lee ML, Vickrey B. A dementia care management intervention: which components improve quality? The American Journal of Managed Care. 2012;18(2): 85-94. Kaisey M, Mittman B, Pearson M, Connor KI, Chodosh J, Vassar SD, Nguyen FT, Vickrey B. Predictors of acceptance of offered care management intervention services in a quality improvement trial for dementia. International Journal of Geriatric Psychiatry. 2012;27: 1078-1085. Brown AF, Vassar SD, Connor KI, Vickrey B. Collaborative care management reduces disparities in dementia care quality for caregiver with less education. American Journal of Geriatric Psychiatry. 2013;61: 243-251.

Appendix 4: Information on components of trial included in the subgroup analyses

Study ID	*Case manager base*	*Case manager professional background*	*Case manager training*	*Contact frequency (average over 12 months)*	*Contact type*	*Supervision*	*Workload (caseload)*
Bass 2003	Community-based	Social Workers	NR	10	Telephone	Yes	01:40
Bass 2014	Both	Social Workers & Nurses	Yes	20	Telephone	Yes	1:75-125
Callahan 2006	Primary Care	Nurse	No	7.7	Face-to-face & telephone	Yes	1:60-80
Chien 2008	Community-based	Nurse	Yes	20	Face-to-face & telephone	No	01:20
Chien 2011	Community-based	Nurse	Yes	24	Face-to-face & telephone	No	01:20
Chu 2000	NR	Social workers	NR	12	Face-to-face & telephone	NR	NR
Dias 2008	Community-based	NR	Yes	24	Face-to-face & telephone	Yes	01:20
Eloniemi-Sulkava 2001	Primary Care	Nurse	Yes	NR	Face-to-face & telephone	No	NR
Eloniemi-Sulkava 2009	NR	Nurse	Yes	NR	Face-to-face & telephone	Yes	1:60
Jansen 2011	Community-based	Nurse	Yes	10.8	Face-to-face & telephone	NR	Varied
Lam 2009	Community-based	Occupational Therapists	NR	39	Face-to-face & telephone	NR	01:59
Newcomer 1999	Both	Social Workers & Nurses	NR	NR	Face-to-face & telephone	Yes	Varied
Samus 2014	Community-based	Social Workers	Yes	24	Face-to-face & telephone	Yes	01:40
Vickrey 2006	Community-based	Social Workers	Yes	10.6	Face-to-face & telephone	NR	01:50

Appendix 5: 10 questions of the CASP quality appraisal tool for RCTs included in the systematic review with meta-analysis and subgroup analysis

Study ID (author date)	1. Did the trial address a clearly focused issue? (Y/ Can't tell/ N)	2. Was the assignment of patients to treatments randomised? (Y/ Can't tell/ N)	3. Were patients, health workers and study personnel blinded? (Y/ Can't tell/ N)	4. Were the groups similar at the start of the trial? (Y/Can't tell/ N)	5. Aside from the experimental intervention, were the groups treated equally? (Y/ Can't tell/ N)
Bass 2003	Y	Y	Y	Can't ell	Y
Bass 2014	Y	Y	Can't tell	N	Y
Callahan 2006	Y	Y	Y	Y	Y
Chien 2008	Y	Y	Y	Y	Y
Chien 2010	Y	Y	Y	Y	Y
Chu 2000	Y	Y	Can't tell	Y	Y
Dias 2008	Y	Y	Y	Y	Y
Eloniemi-Sulkava 2001	Y	Y	N	Y	Y
Eloniemi-Sulkava 2009	Y	Y	N	Y	Y
Jansen 2011	Y	Y	Y	Y	Y
Lam 2009	Y	Y	Y	Y	Y
Newcomer 1999	Y	Y	Can't tell	Y	Y
Samus 2014	Y	Y	Y	Y	Y
Vickrey 2006	Y	Y	Y	Y	Y

Study ID (author date)	6. Were all of the patients who entered the trial properly accounted for at it's conclusion? (Y/ Can't tell/ N)	7. How large was the treatment effect?	8. How precise was the estimate of the treatment effect?	9. Can the results be applied in your context? (Y/ Can't tell/ N)	10. Were all clinically important outcomes considered? (Y/Can't Tell/N)	11. Are the benefits worth the harms and costs? (Y/Can't Tell/N)
Bass 2003	Y	Significant for some	Partially/ mostly	Y	Y	Y
Bass 2014	Y	Small (early follow-up)	Partially	Y	N	Y
Callahan 2006	Y	Significant for some	Partially	Y	Y	Y
Chien 2008	N	Significant	Yes	Y	Y	Y
Chien 2010	Y	Significant	Yes	Y	Y	Y
Chu 2000	Y	Significant for some	Partially	Y	Can't Tell	Y
Dias 2008	Y	Significant for some	Partially/ mostly	Y	N	Y
Eloniemi-Sulkava 2001	Y	Small (early follow-up)	Partially	Y	N	Y
Eloniemi-Sulkava 2009	Y	Small (early follow-up)	Partially	Y	N	Y
Jansen 2011	Y	Some/ None	Not precise	Y	Y	N
Lam 2009	Y	Small (early follow-up)	Partially	Y	Y	Y
Newcomer 1999	Can't tell	Significant for some	Partially	Y	Y	Y
Samus 2014	Y	Significant for some	Partially	Y	Y	Y
Vickrey 2006	Y	Significant for some	Partially/ mostly	Y	Y	Y

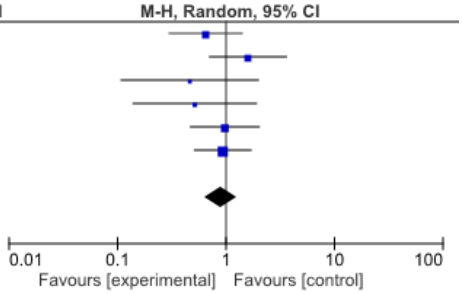
Appendix 6: Forest plots for results of the meta-analyses and subgroup analyses

Meta-analyses comparison: Coordination intervention versus control

Outcome 1: Hospitalisation

Study or Subgroup	Experimental Events	Experimental Total	Control Events	Control Total	Weight	Odds Ratio M-H, Random, 95% CI
Bass 2003	17	94	16	63	18.7%	0.65 [0.30, 1.41]
Callahan 2006	19	64	13	62	16.9%	1.59 [0.71, 3.59]
Chien & Lee 2008	3	44	6	44	5.3%	0.46 [0.11, 1.98]
Chien & Lee 2011	4	45	7	44	6.6%	0.52 [0.14, 1.90]
Eloniemi-Sulkava 2009	23	63	23	62	21.2%	0.97 [0.47, 2.02]
Vickrey 2006	36	116	28	86	31.3%	0.93 [0.51, 1.70]
Total (95% CI)		**426**		**361**	**100.0%**	**0.89 [0.64, 1.25]**
Total events	102		93			

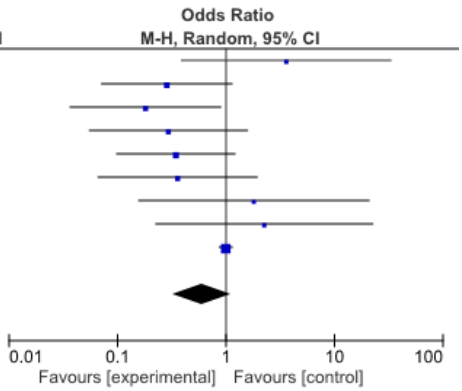
Heterogeneity: Tau² = 0.00; Chi² = 4.13, df = 5 (P = 0.53); I² = 0%
Test for overall effect: Z = 0.67 (P = 0.50)



Outcome 2: Institutionalisation

Study or Subgroup	Experimental Events	Experimental Total	Control Events	Control Total	Weight	Odds Ratio M-H, Random, 95% CI
Callahan 2006	4	72	1	62	6.2%	3.59 [0.39, 32.99]
Chien & Lee 2008	3	44	9	44	12.0%	0.28 [0.07, 1.13]
Chien & Lee 2011	2	45	9	44	10.0%	0.18 [0.04, 0.89]
Chu 2000	2	36	6	36	9.4%	0.29 [0.06, 1.57]
Eloniemi-Sulkava 2001	4	53	9	47	13.4%	0.34 [0.10, 1.21]
Eloniemi-Sulkava 2009	2	59	5	56	9.3%	0.36 [0.07, 1.93]
Jansen 2011	2	43	1	38	5.3%	1.80 [0.16, 20.73]
Lam 2009	3	59	1	43	5.9%	2.25 [0.23, 22.40]
Newcomer 1999	563	2682	533	2527	28.5%	0.99 [0.87, 1.14]
Total (95% CI)		**3093**		**2897**	**100.0%**	**0.60 [0.32, 1.11]**
Total events	585		574			

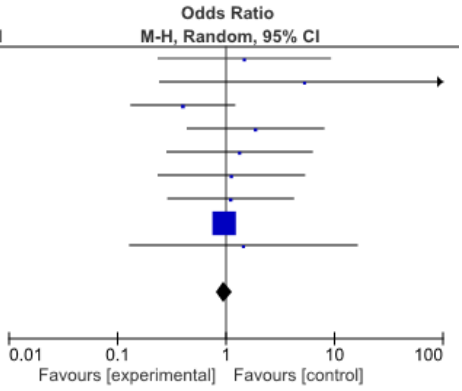
Heterogeneity: Tau² = 0.35; Chi² = 15.40, df = 8 (P = 0.05); I² = 48%
Test for overall effect: Z = 1.63 (P = 0.10)



Outcome 3: Mortality

Study or Subgroup	Experimental Events	Experimental Total	Control Events	Control Total	Weight	Odds Ratio M-H, Random, 95% CI
Callahan 2006	3	64	2	62	1.0%	1.48 [0.24, 9.15]
Chu 2000	2	37	0	37	0.4%	5.28 [0.24, 113.87]
Dias 2008	6	41	12	40	2.8%	0.40 [0.13, 1.20]
Eloniemi-Sulkava 2001	6	53	3	47	1.6%	1.87 [0.44, 7.95]
Eloniemi-Sulkava 2009	4	63	3	62	1.4%	1.33 [0.29, 6.22]
Jansen 2011	4	54	3	45	1.4%	1.12 [0.24, 5.29]
Lam 2009	6	59	4	43	1.9%	1.10 [0.29, 4.18]
Newcomer 1999	225	2682	220	2527	89.0%	0.96 [0.79, 1.17]
Vickrey 2006	2	161	1	116	0.6%	1.45 [0.13, 16.14]
Total (95% CI)		**3214**		**2979**	**100.0%**	**0.97 [0.81, 1.16]**
Total events	258		248			

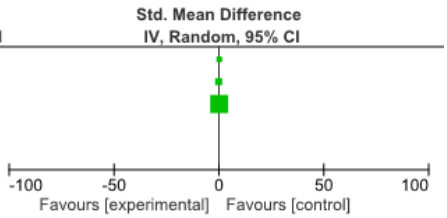
Heterogeneity: Tau² = 0.00; Chi² = 5.01, df = 8 (P = 0.76); I² = 0%
Test for overall effect: Z = 0.34 (P = 0.73)



Outcome 4: Patient quality of life

Study or Subgroup	Experimental Mean	SD	Total	Control Mean	SD	Total	Weight	Std. Mean Difference IV, Random, 95% CI
Jansen 2011	0.09	1.38	30	-0.17	1.37	28	12.3%	0.19 [-0.33, 0.70]
Lam 2009	-5.48	24.83	53	-2.49	18.93	39	19.1%	-0.13 [-0.55, 0.28]
Vickrey 2006	0.1	0.31	187	0.06	0.31	142	68.6%	0.13 [-0.09, 0.35]
Total (95% CI)			**270**			**209**	**100.0%**	**0.09 [-0.09, 0.27]**

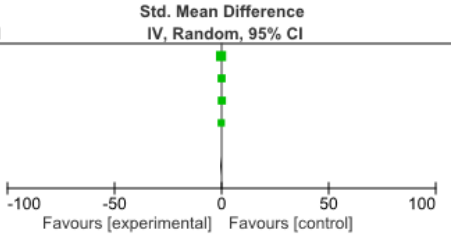
Heterogeneity: Tau² = 0.00; Chi² = 1.35, df = 2 (P = 0.51); I² = 0%
Test for overall effect: Z = 0.93 (P = 0.35)



Outcome 5: Patient cognition

Study or Subgroup	Experimental Mean	SD	Total	Control Mean	SD	Total	Weight	Std. Mean Difference IV, Random, 95% CI
Callahan 2006	14.6	8.2	64	16.7	8.9	62	32.8%	-0.24 [-0.59, 0.11]
Chien 2008	19	5.8	44	19.1	4.8	44	23.1%	-0.02 [-0.44, 0.40]
Chien 2011	19.8	5.8	46	19.1	4.8	46	24.0%	0.13 [-0.28, 0.54]
Eloniemi-Sulkava 2001	12.6	6.1	43	13.6	5.7	35	20.1%	-0.17 [-0.61, 0.28]
Total (95% CI)			**197**			**187**	**100.0%**	**-0.09 [-0.29, 0.11]**

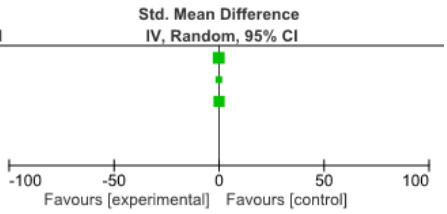
Heterogeneity: Tau² = 0.00; Chi² = 2.08, df = 3 (P = 0.56); I² = 0%
Test for overall effect: Z = 0.85 (P = 0.40)



Outcome 6: Patient function

Study or Subgroup	Experimental Mean	SD	Total	Control Mean	SD	Total	Weight	Std. Mean Difference IV, Random, 95% CI
Callahan 2006	47	16.7	72	49.3	8.8	62	42.0%	-0.17 [-0.51, 0.17]
Dias 2008	8.5	2.3	33	8.7	2.2	26	18.4%	-0.09 [-0.60, 0.43]
Eloniemi-Sulkava 2009	67.4	22.47	63	66.3	141.1	62	39.6%	0.01 [-0.34, 0.36]
Total (95% CI)			**168**			**150**	**100.0%**	**-0.08 [-0.30, 0.14]**

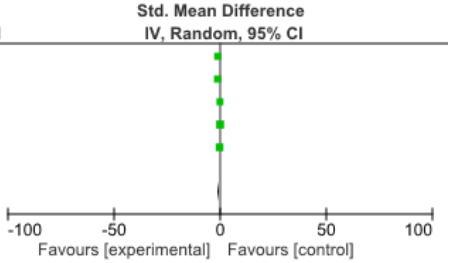
Heterogeneity: Tau² = 0.00; Chi² = 0.51, df = 2 (P = 0.77); I² = 0%
Test for overall effect: Z = 0.73 (P = 0.46)



Outcome 7: Caregiver burden

Study or Subgroup	Experimental Mean	SD	Total	Control Mean	SD	Total	Weight	Std. Mean Difference IV, Random, 95% CI
Chien 2008	48.3	13.9	44	65.9	16.3	44	18.9%	-1.15 [-1.60, -0.70]
Chien 2011	48.1	13	46	65.3	15.3	46	19.0%	-1.20 [-1.65, -0.76]
Dias 2008	19	13	33	21.4	16.2	26	18.0%	-0.16 [-0.68, 0.35]
Newcomer 1999	14.1	8.07	1702	14.4	8.62	1597	22.9%	-0.04 [-0.10, 0.03]
Samus 2014	13.9	8.52	74	16.14	8.44	114	21.1%	-0.26 [-0.56, 0.03]
Total (95% CI)			**1899**			**1827**	**100.0%**	**-0.54 [-1.01, -0.07]**

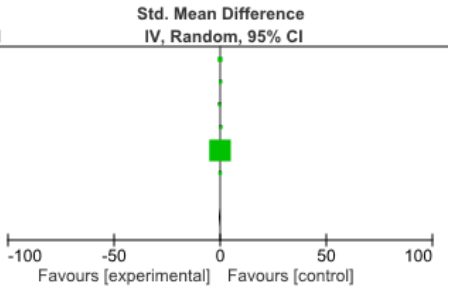
Heterogeneity: Tau² = 0.25; Chi² = 48.82, df = 4 (P < 0.00001); I² = 92%
Test for overall effect: Z = 2.26 (P = 0.02)



Outcome 8: Caregiver mood

Study or Subgroup	Experimental Mean	SD	Total	Control Mean	SD	Total	Weight	Std. Mean Difference IV, Random, 95% CI
Bass 2014	4.7	8.6	299	5	10.3	187	8.7%	-0.03 [-0.21, 0.15]
Callahan 2006	4.3	5.1	72	3.6	5	62	2.5%	0.14 [-0.20, 0.48]
Chu 2000	8	8.6	21	11.1	10.3	26	0.9%	-0.32 [-0.90, 0.26]
Jansen 2011	11.9	8.6	45	9.7	10.3	41	1.6%	0.23 [-0.19, 0.66]
Newcomer 1999	4.29	3.42	2269	4.48	3.52	2139	83.0%	-0.05 [-0.11, 0.00]
Samus 2014	2.93	2.92	74	3.01	2.99	114	3.4%	-0.03 [-0.32, 0.27]
Total (95% CI)			**2780**			**2569**	**100.0%**	**-0.04 [-0.10, 0.01]**

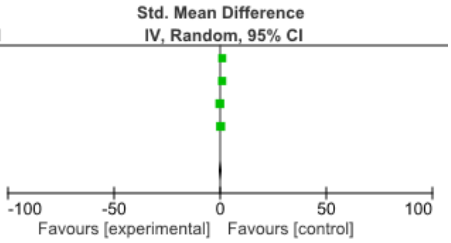
Heterogeneity: Tau² = 0.00; Chi² = 3.72, df = 5 (P = 0.59); I² = 0%
Test for overall effect: Z = 1.63 (P = 0.10)



Outcome 9: Caregiver quality of life

Study or Subgroup	Experimental Mean	SD	Total	Control Mean	SD	Total	Weight	Std. Mean Difference IV, Random, 95% CI
Chien 2008	81.4	16	44	65.2	17.5	44	23.2%	0.96 [0.52, 1.40]
Chien 2011	80.4	15	46	65.2	17.5	46	23.4%	0.92 [0.49, 1.36]
Samus 2014	32.2	5.29	78	33.1	5.88	138	26.2%	-0.16 [-0.44, 0.12]
Vickrey 2006	0.83	0.18	205	0.79	0.22	156	27.2%	0.20 [-0.01, 0.41]
Total (95% CI)			**373**			**384**	**100.0%**	**0.45 [-0.03, 0.94]**

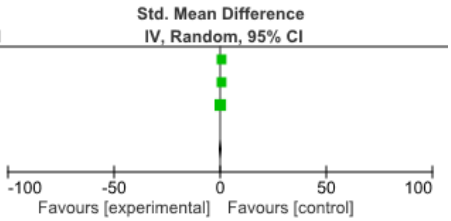
Heterogeneity: Tau² = 0.21; Chi² = 27.68, df = 3 (P < 0.00001); I² = 89%
Test for overall effect: Z = 1.83 (P = 0.07)



Outcome 10: Social support

Study or Subgroup	Experimental Mean	SD	Total	Control Mean	SD	Total	Weight	Std. Mean Difference IV, Random, 95% CI
Chien 2008	6.7	2.1	44	5.4	2.1	44	30.6%	0.61 [0.19, 1.04]
Chien 2011	6.7	2.1	46	5.4	2.1	46	31.0%	0.61 [0.20, 1.03]
Vickrey 2006	69.9	25.2	205	69.6	27.6	156	38.4%	0.01 [-0.20, 0.22]
Total (95% CI)			**295**			**246**	**100.0%**	**0.38 [-0.08, 0.84]**

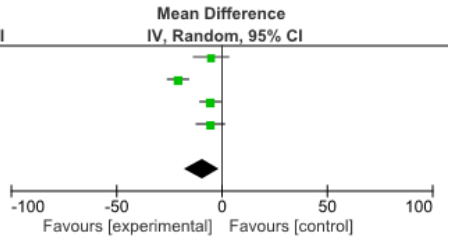
Heterogeneity: Tau² = 0.13; Chi² = 10.49, df = 2 (P = 0.005); I² = 81%
Test for overall effect: Z = 1.63 (P = 0.10)



Outcome 11: Patient behaviour

Study or Subgroup	Experimental Mean	SD	Total	Control Mean	SD	Total	Weight	Mean Difference IV, Random, 95% CI
Callahan 2006	-2.5	17.62	64	2.7	28.74	62	22.7%	-5.20 [-13.56, 3.16]
Chien 2008	64.2	11.8	44	85.1	12.1	44	26.3%	-20.90 [-25.89, -15.91]
Chien 2011	76.3	11.8	46	81.9	12.1	46	26.4%	-5.60 [-10.48, -0.72]
Lam 2009	4.62	17.23	53	10.15	15.43	39	24.6%	-5.53 [-12.24, 1.18]
Total (95% CI)			**207**			**191**	**100.0%**	**-9.52 [-18.05, -1.00]**

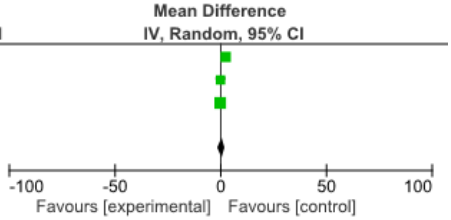
Heterogeneity: Tau² = 65.35; Chi² = 24.16, df = 3 (P < 0.0001); I² = 88%
Test for overall effect: Z = 2.19 (P = 0.03)



Outcome 12: Patient depression

Study or Subgroup	Experimental Mean	SD	Total	Control Mean	SD	Total	Weight	Mean Difference IV, Random, 95% CI
Callahan 2006	5.8	5.9	64	3.5	3.9	62	32.8%	2.30 [0.56, 4.04]
Lam 2009	0.94	6.47	53	1.08	3.57	39	28.6%	-0.14 [-2.21, 1.93]
Samus 2014	5.9	4.62	76	6.2	4.76	135	38.7%	-0.30 [-1.61, 1.01]
Total (95% CI)			**193**			**236**	**100.0%**	**0.60 [-1.08, 2.27]**

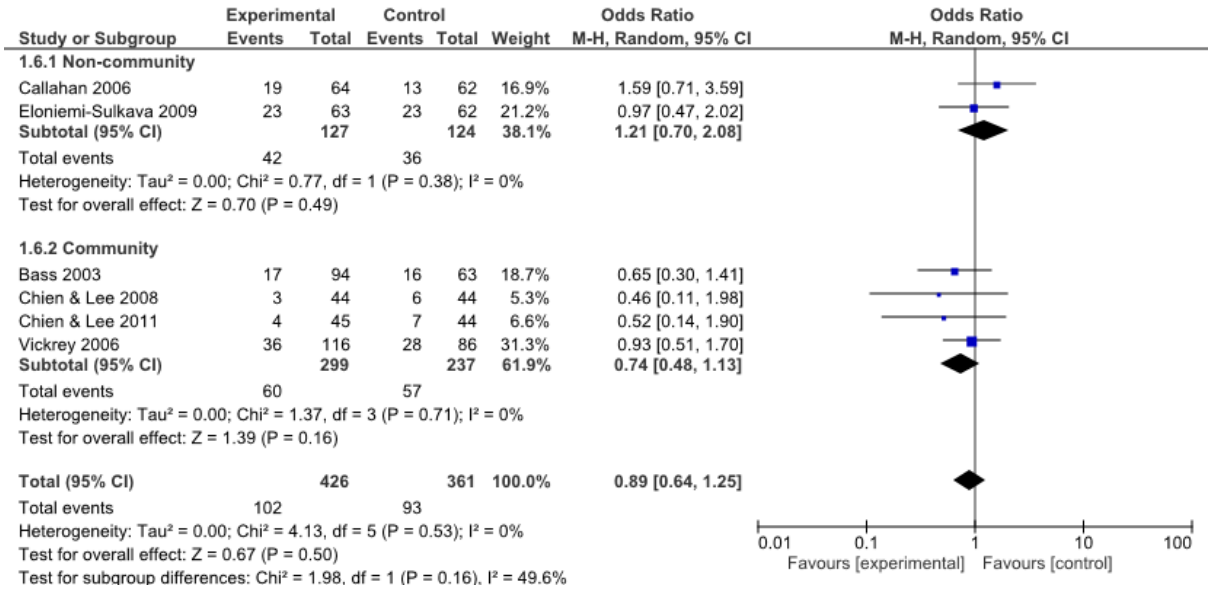
Heterogeneity: Tau² = 1.44; Chi² = 5.90, df = 2 (P = 0.05); I² = 66%
Test for overall effect: Z = 0.70 (P = 0.48)



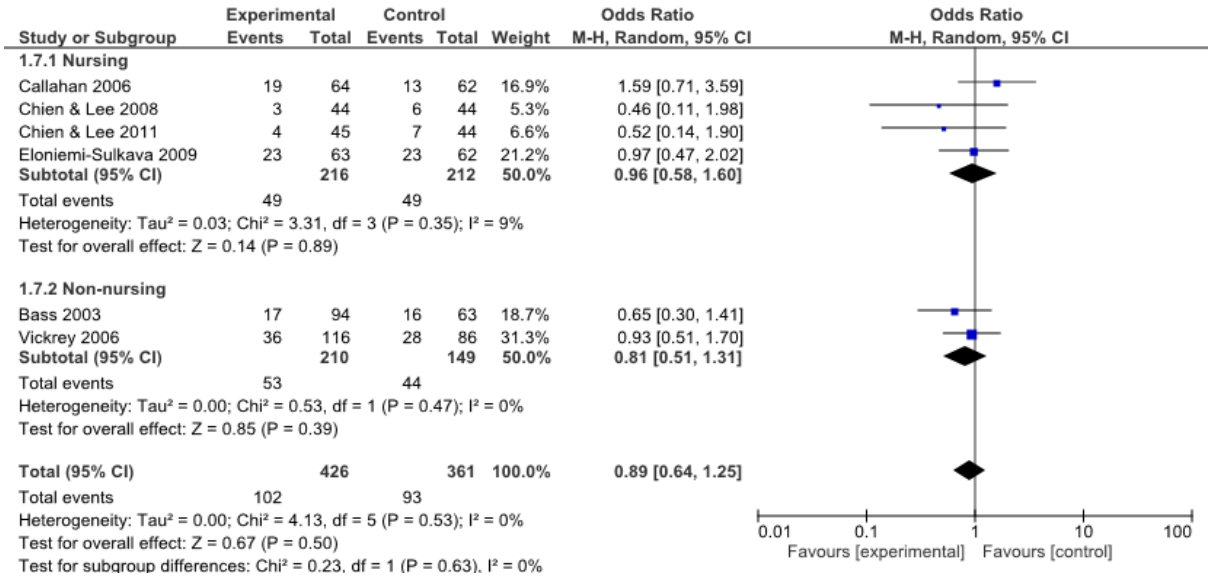
Subgroup analyses

Outcome 1: Hospitalisation

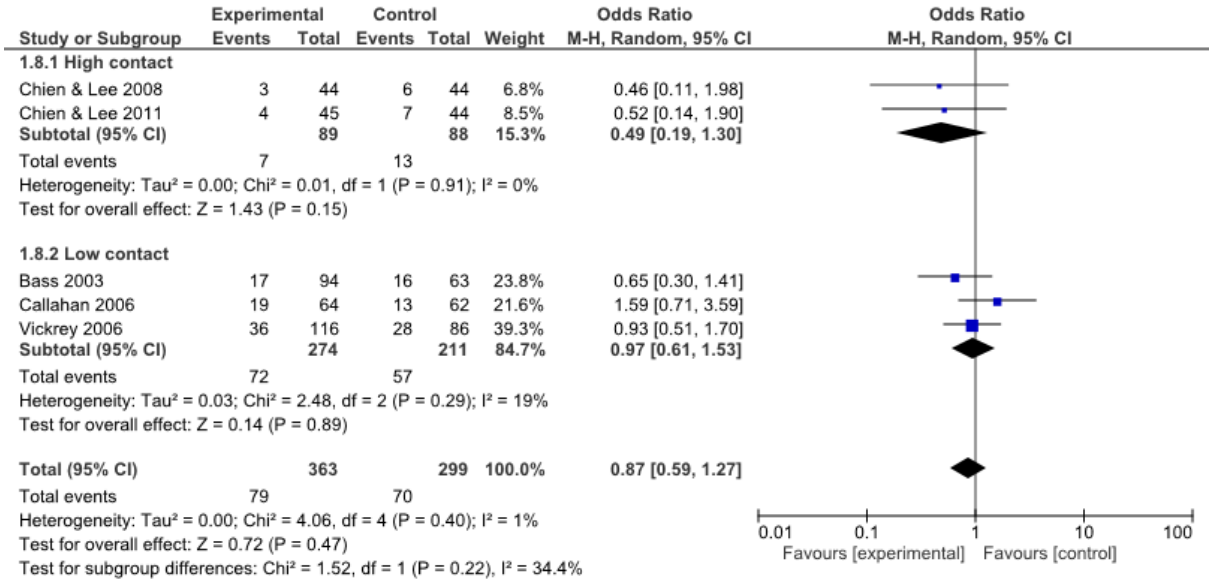
Comparison 1: Community base versus non-community base case managers



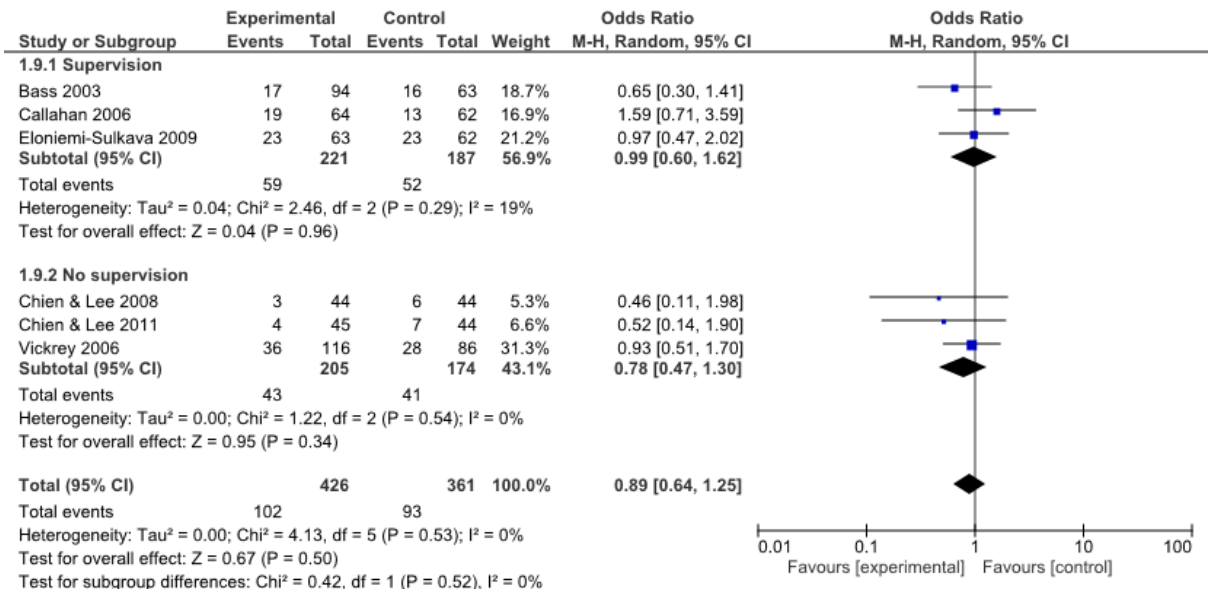
Comparison 2: Nursing versus non-nursing background of case managers



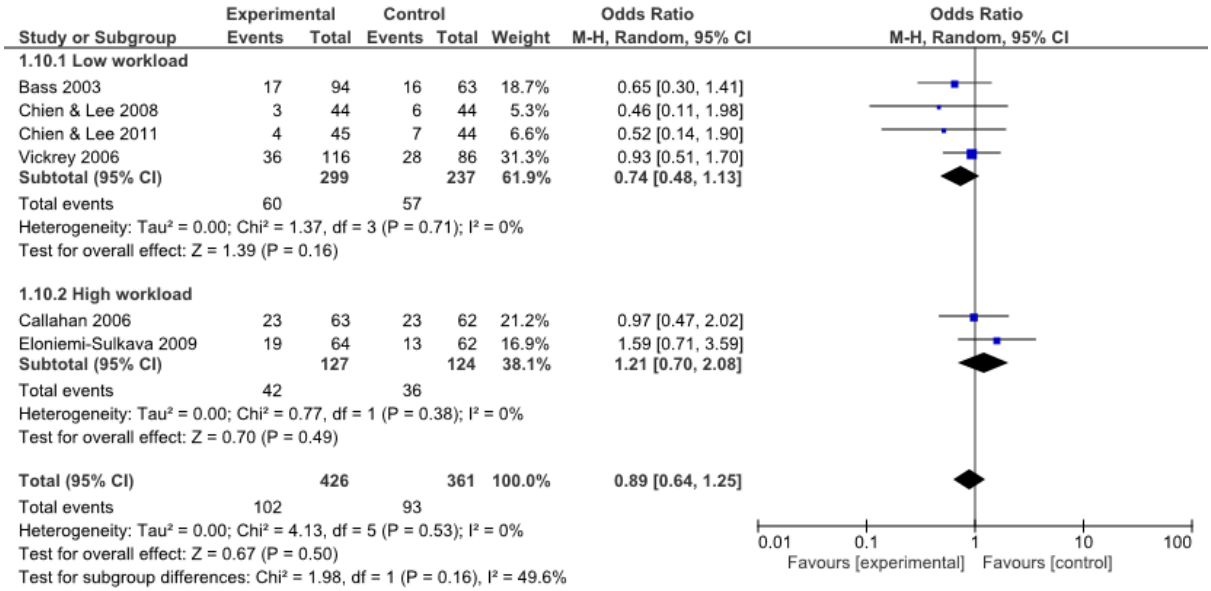
Comparison 3: High contact versus low contact frequency



Comparison 4: Supervision versus no supervision

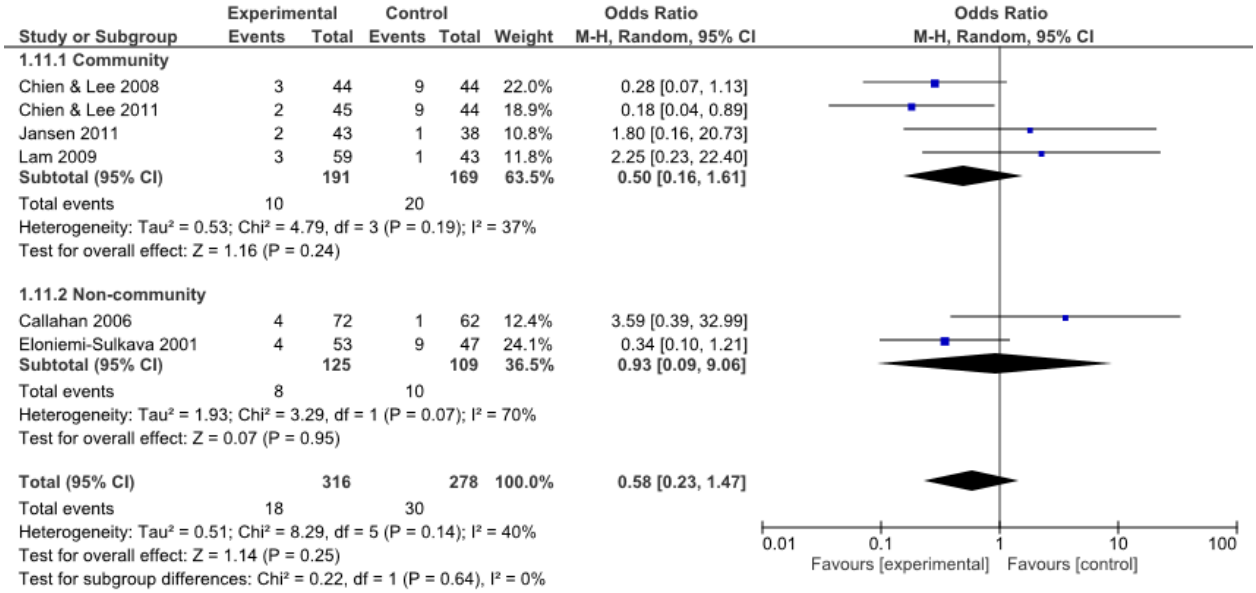


Comparison 5: Low workload versus high workload

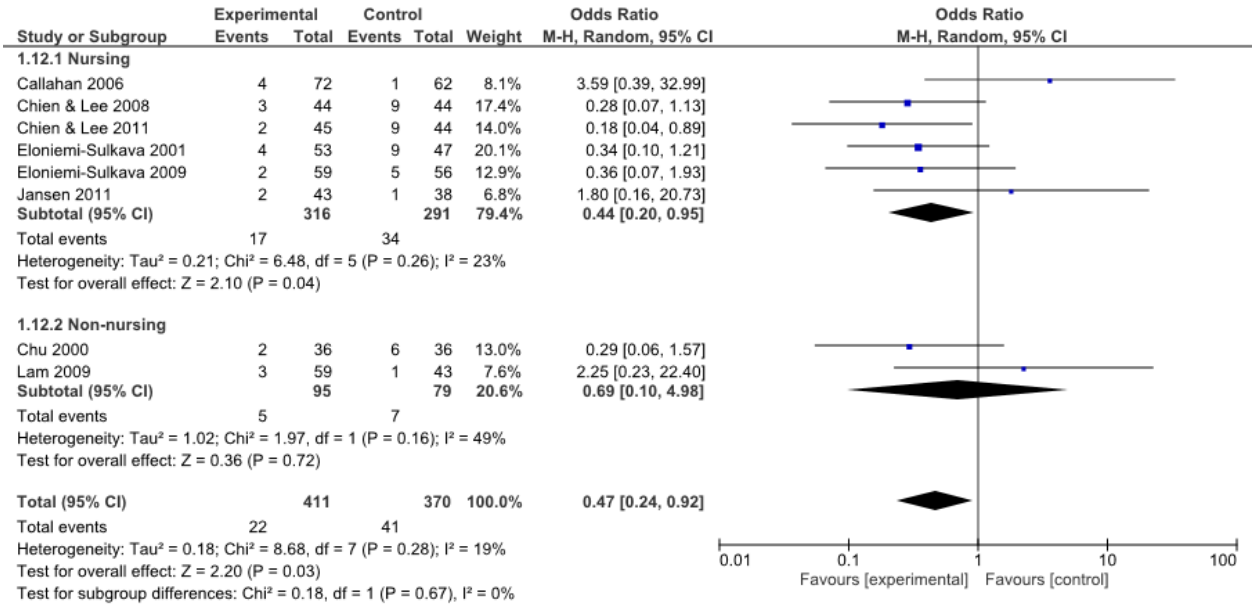


Outcome 2: Institutionalisation

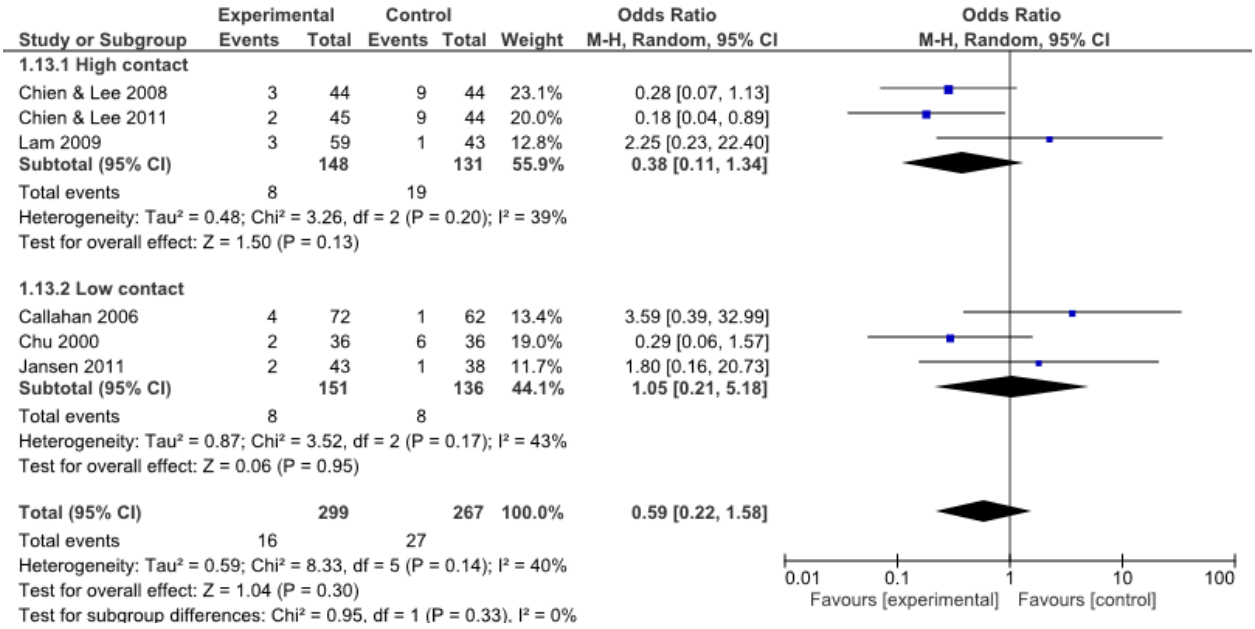
Comparison 1: Community base versus non-community base case managers



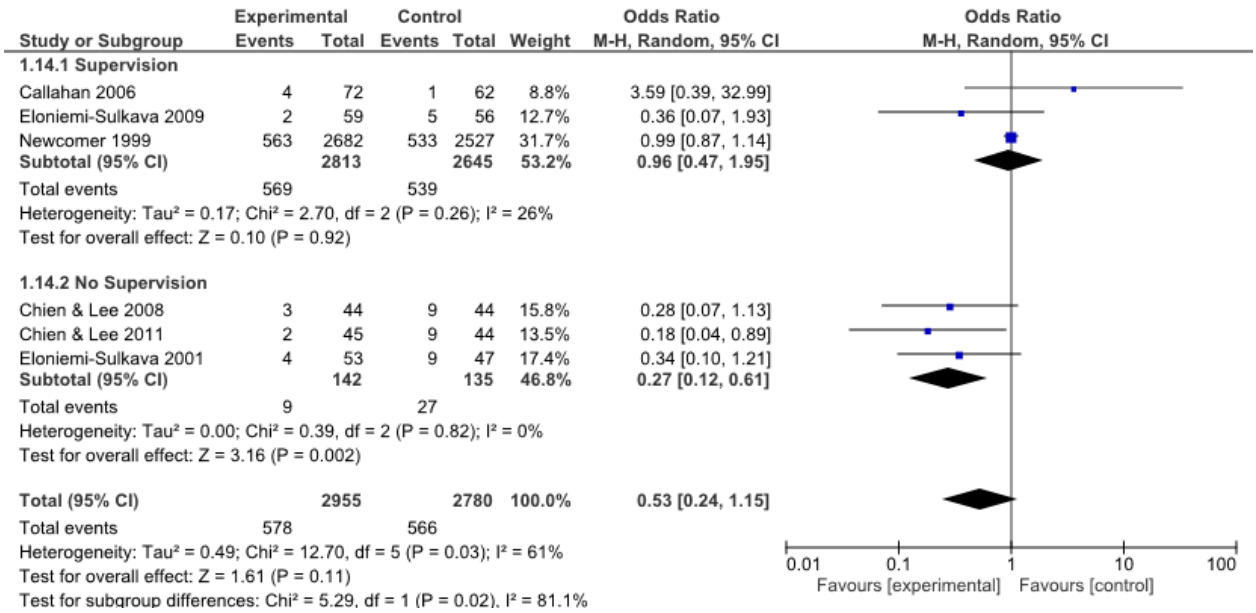
Comparison 2: Nursing versus non-nursing background of case managers



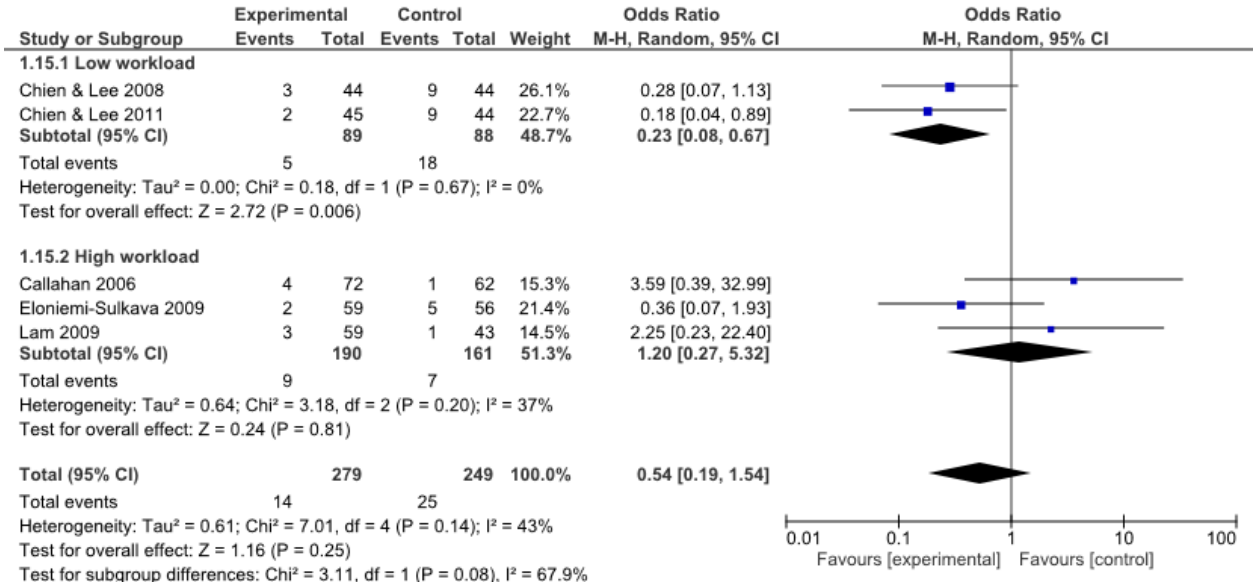
Comparison 3: High contact versus low contact frequency



Comparison 4: Supervision versus no supervision

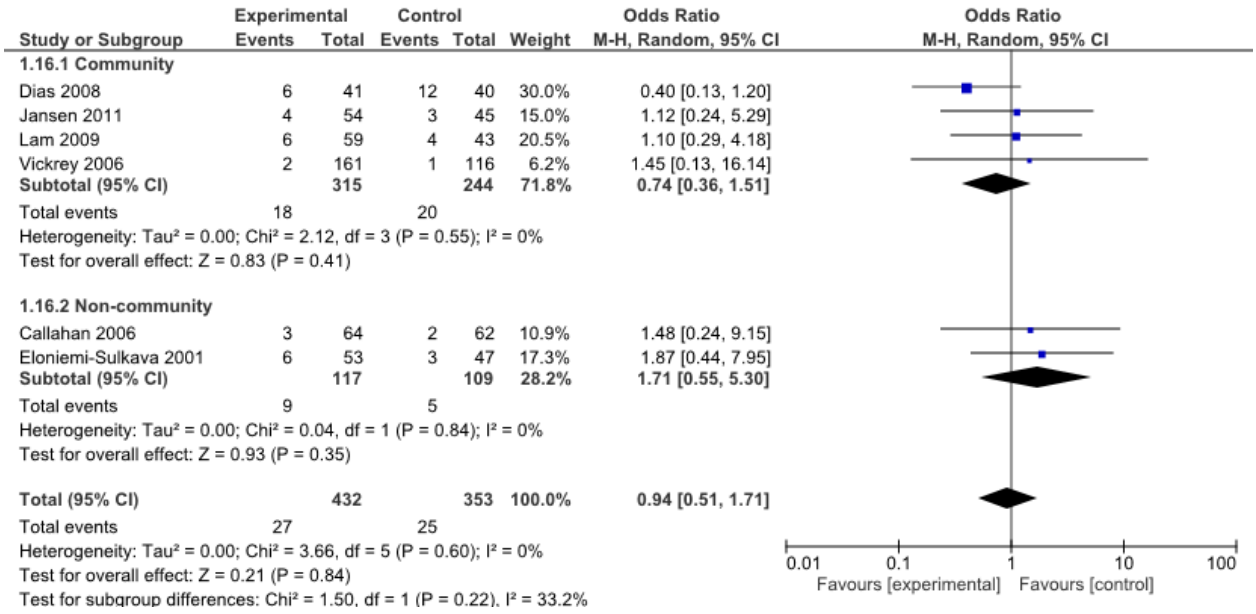


Comparison 5: Low workload versus high workload

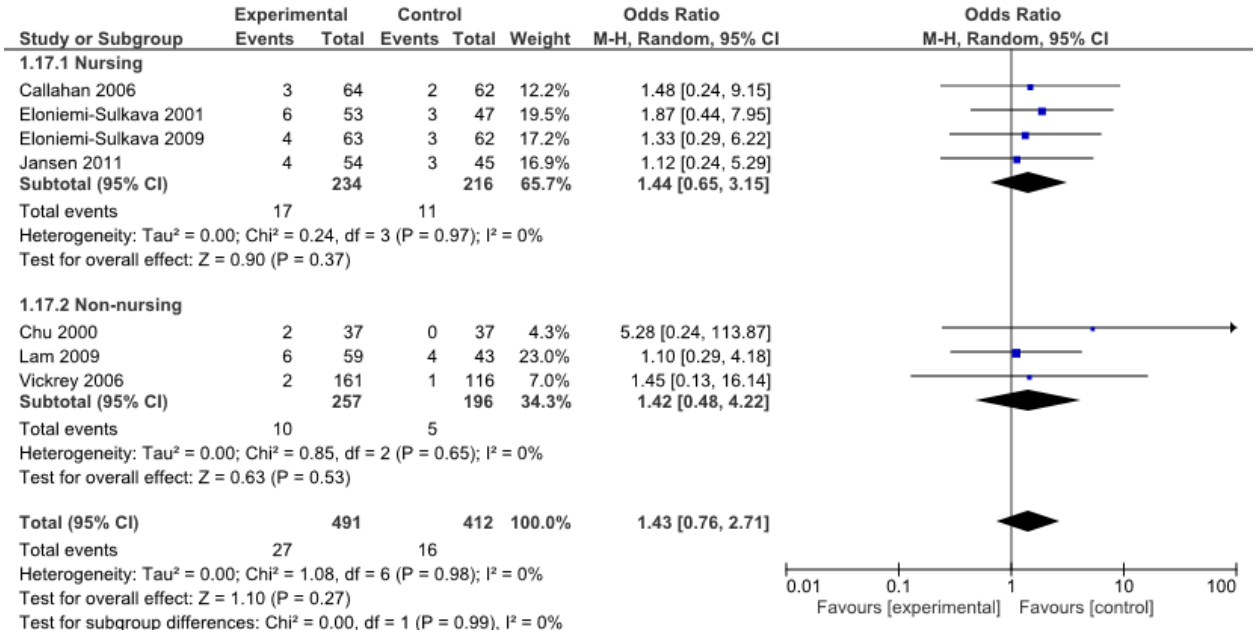


Outcome 3: Mortality

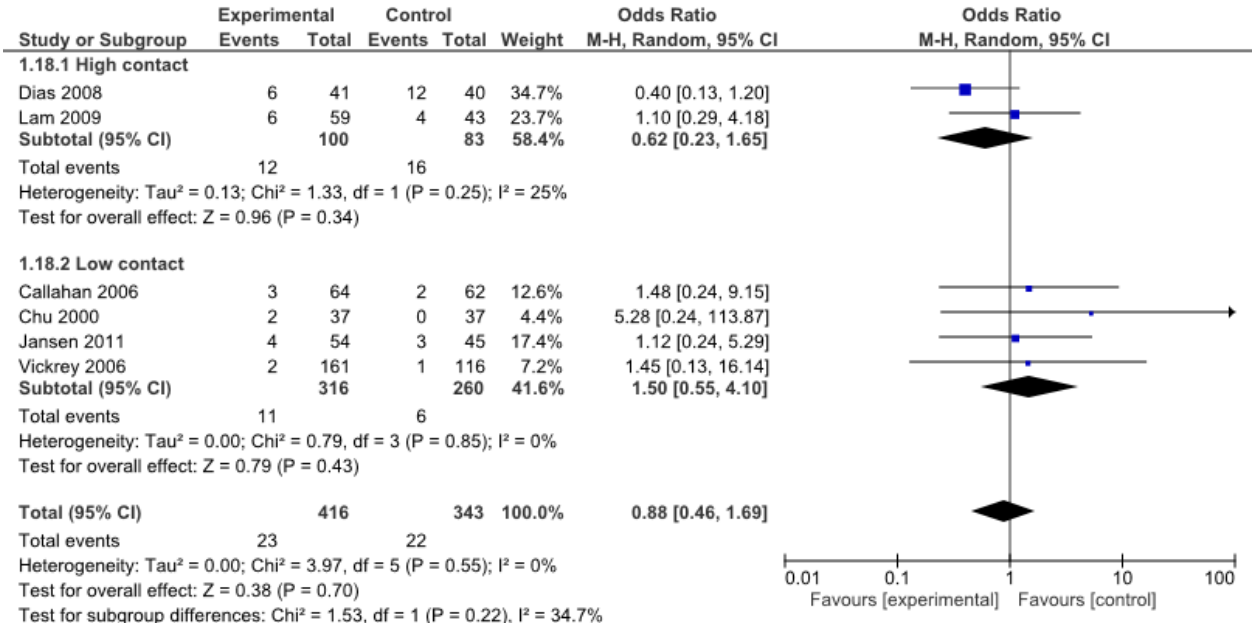
Comparison 1: Community base versus non-community base case managers



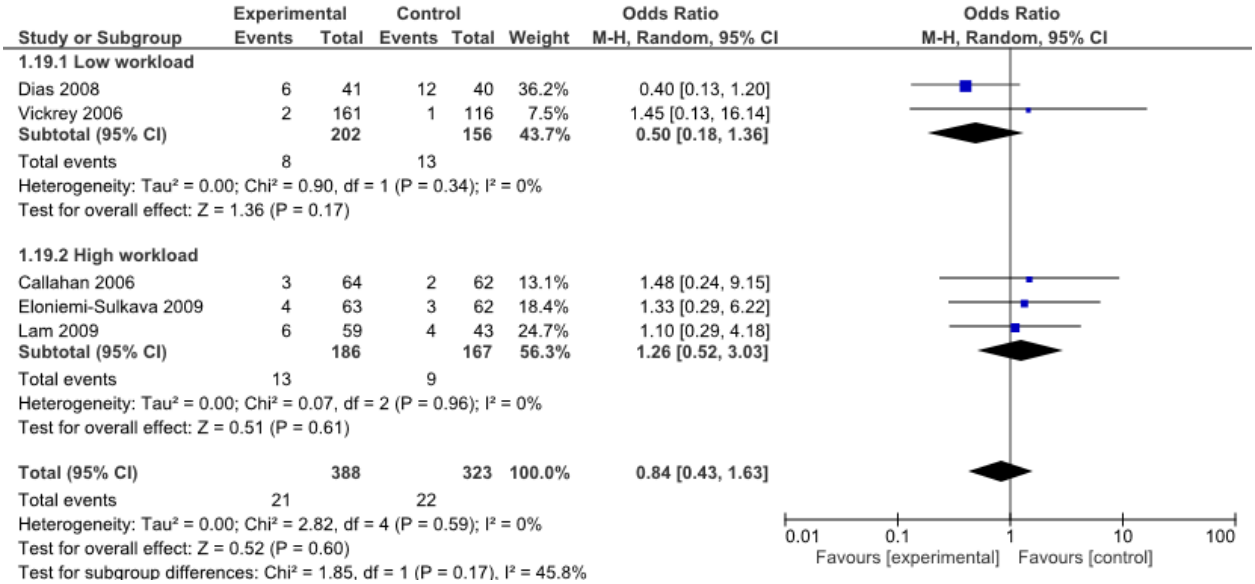
Comparison 2: Nursing versus non-nursing background of case managers



Comparison 3: High contact versus low contact frequency

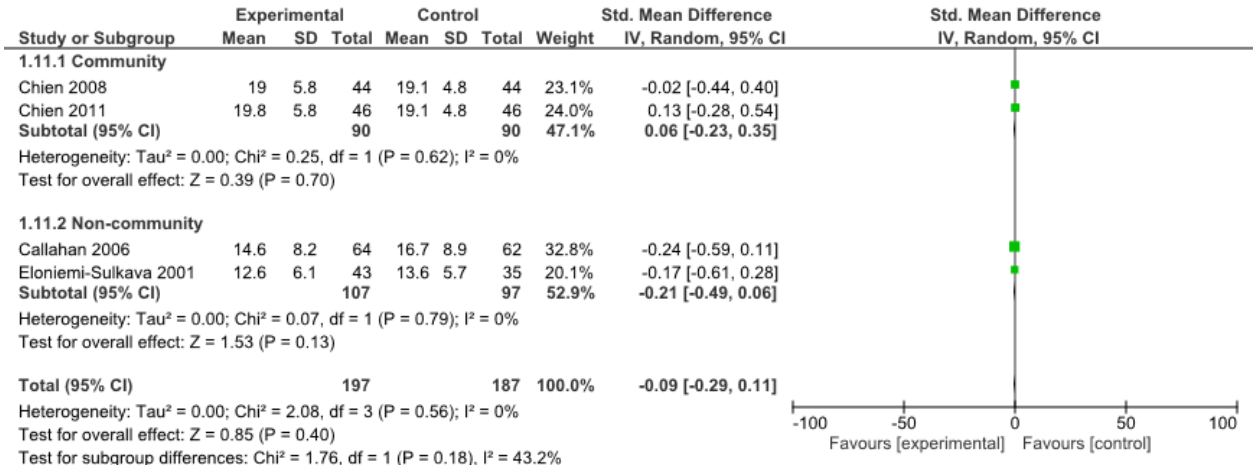


Comparison 4: Low workload versus high workload



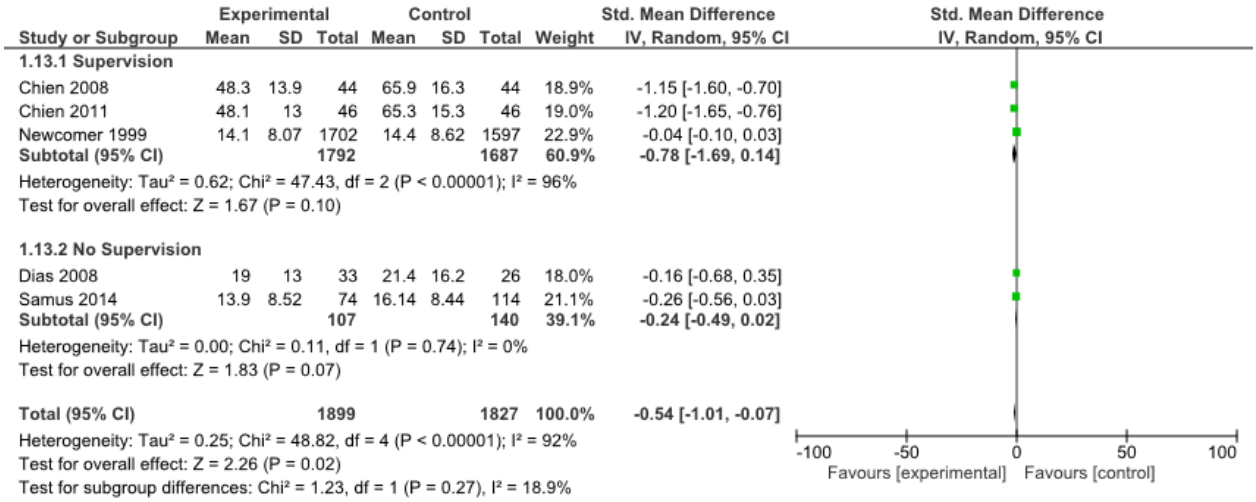
Outcome 4: Patient cognition

Comparison 1: Community base versus non-community base case managers



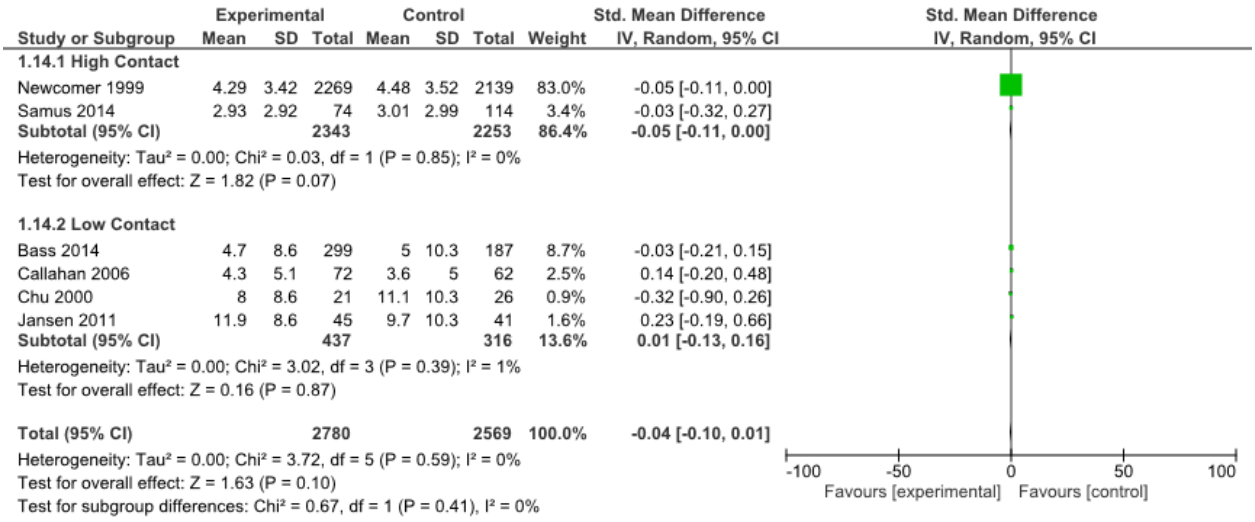
Outcome 5: Caregiver burden

Comparison 1: Supervision versus no supervision



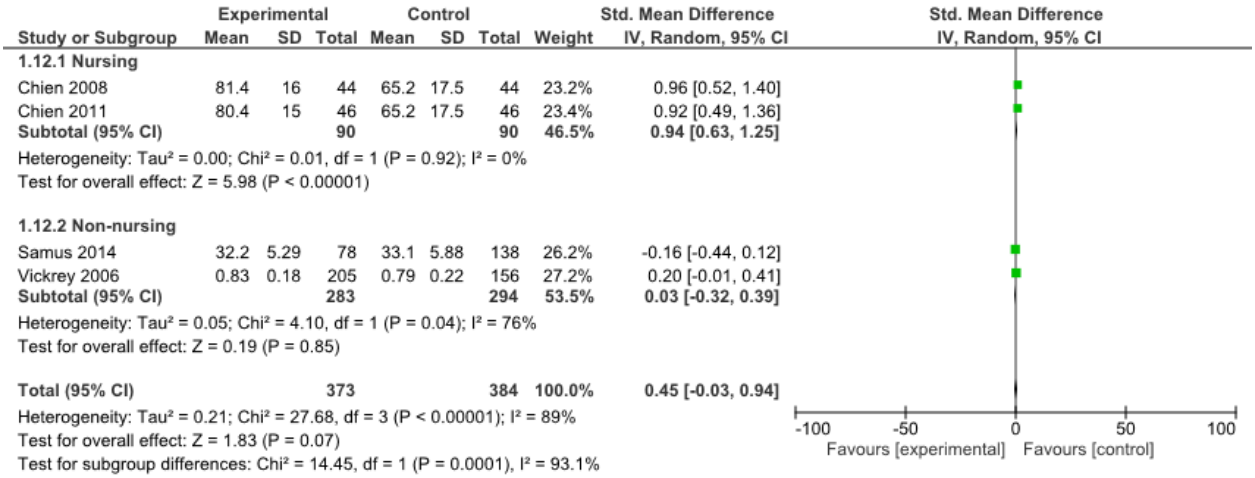
Outcome 6: Caregiver mood

Comparison 1: High contact versus low contact frequency



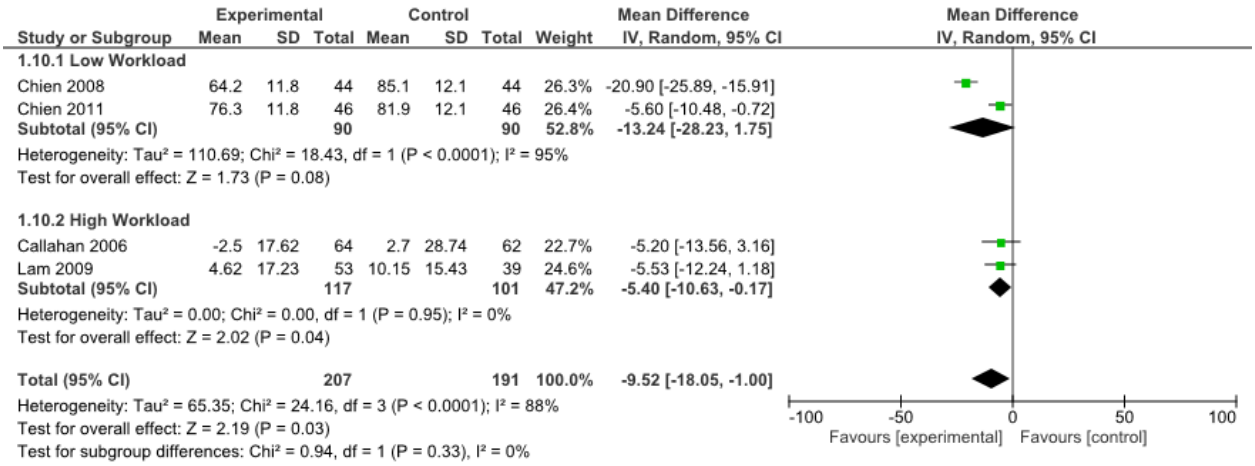
Outcome 7: Caregiver quality of life

Comparison 1: Nursing versus non-nursing background of case managers



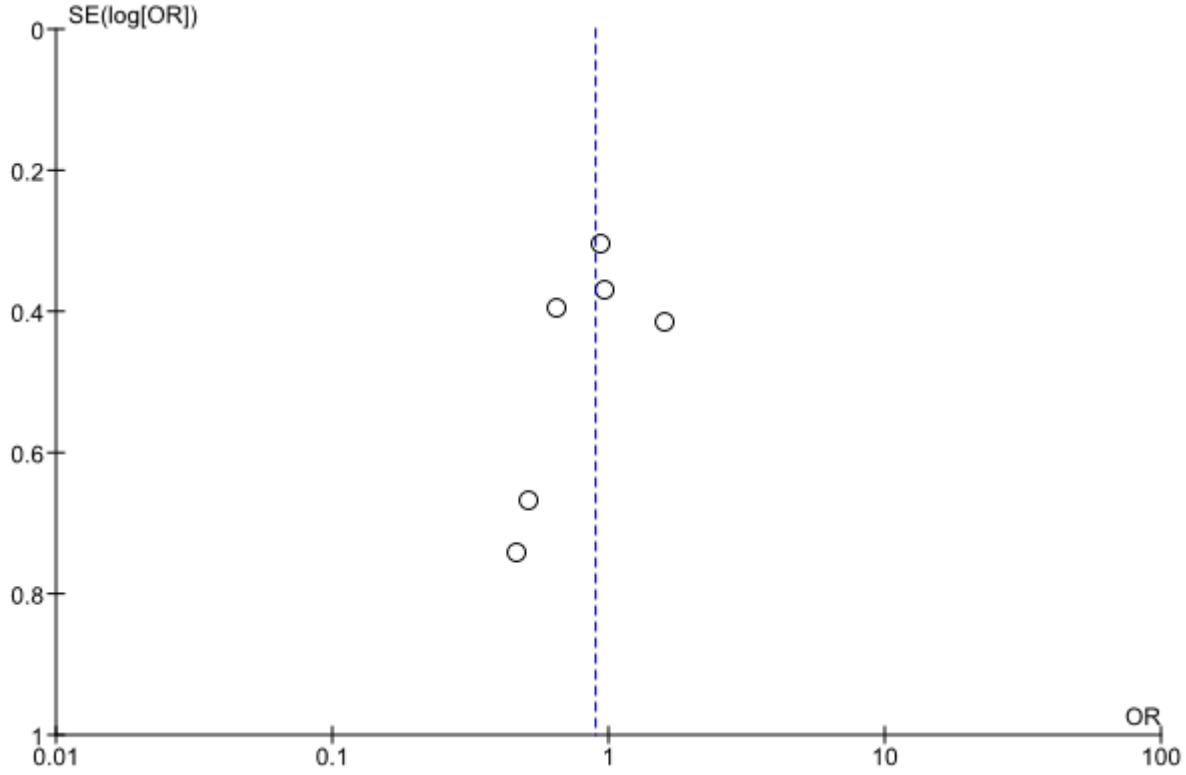
Outcome 8: Patient behaviour

Comparison 1: Low workload versus high workload

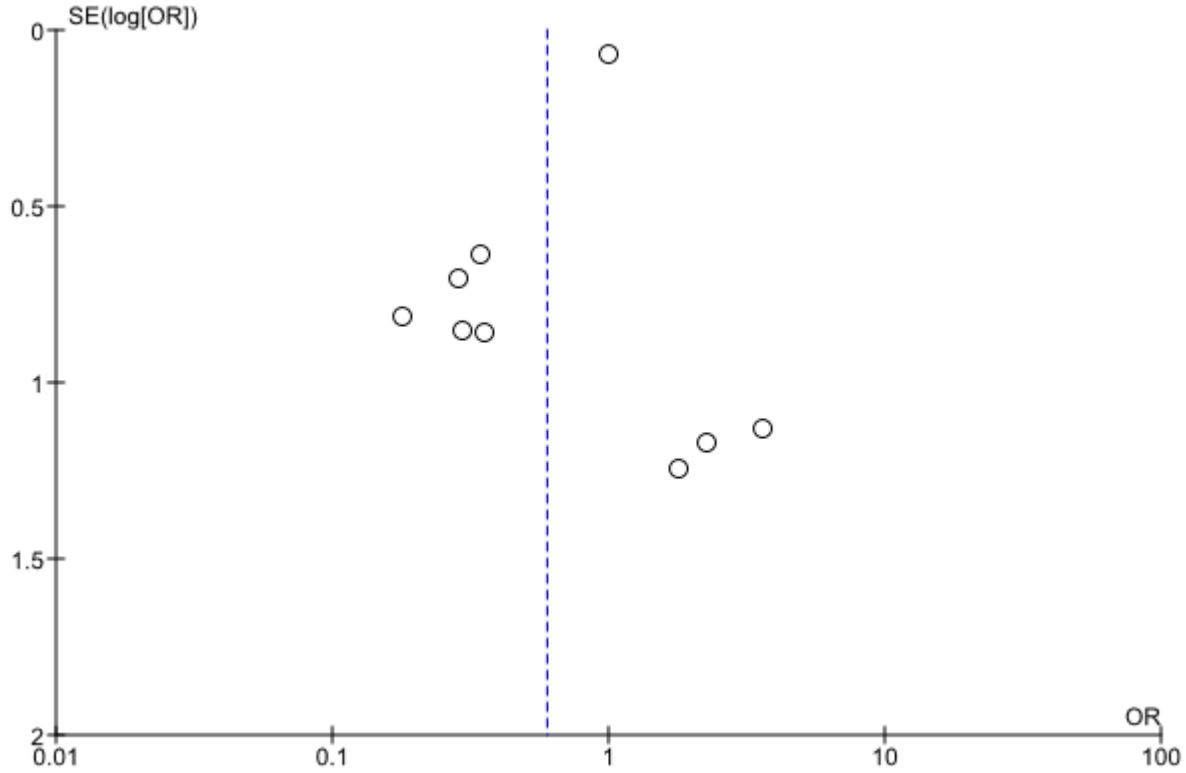


Appendix 7: Funnel plots used to evaluate publication bias

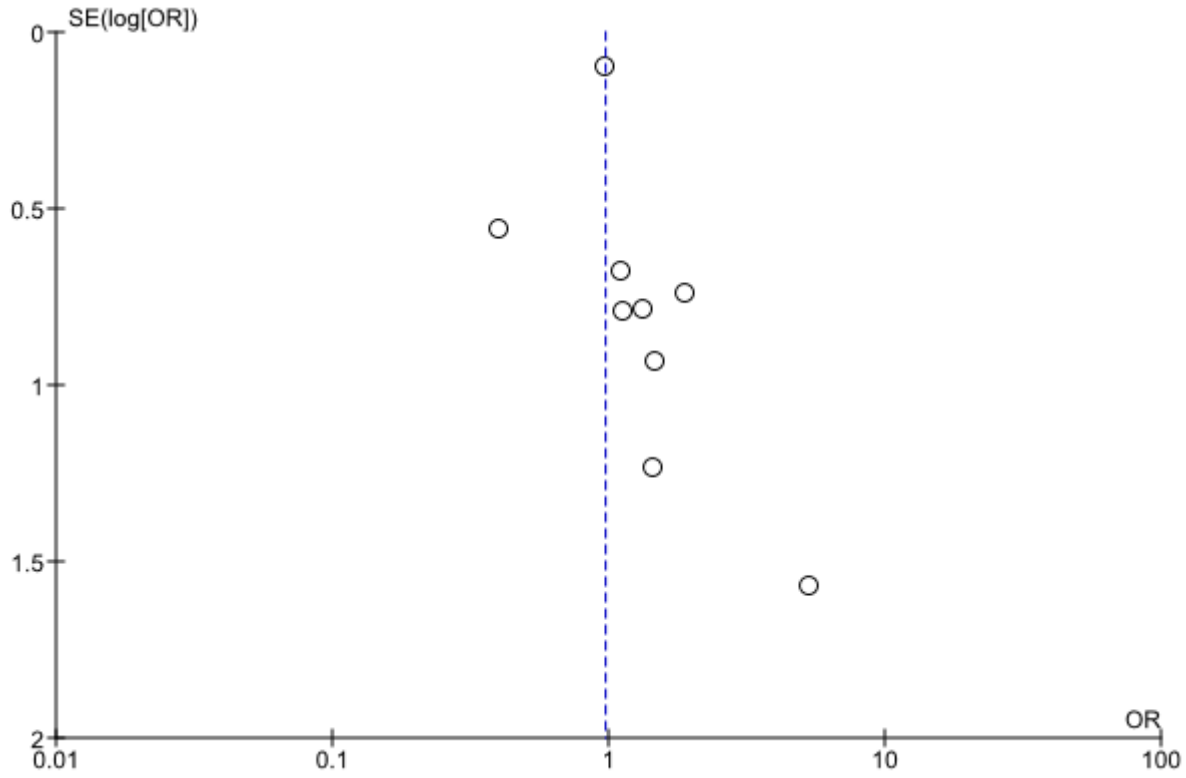
Outcome 1: Hospitalisation



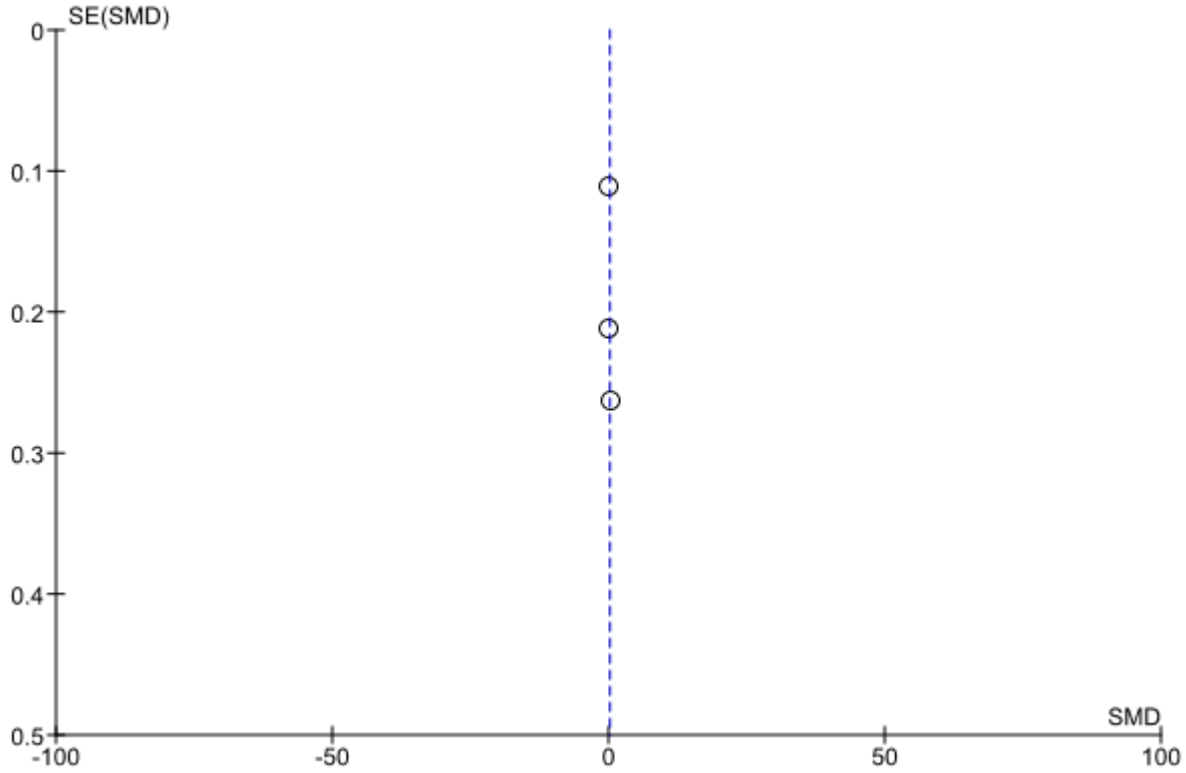
Outcome 2: Institutionalisation



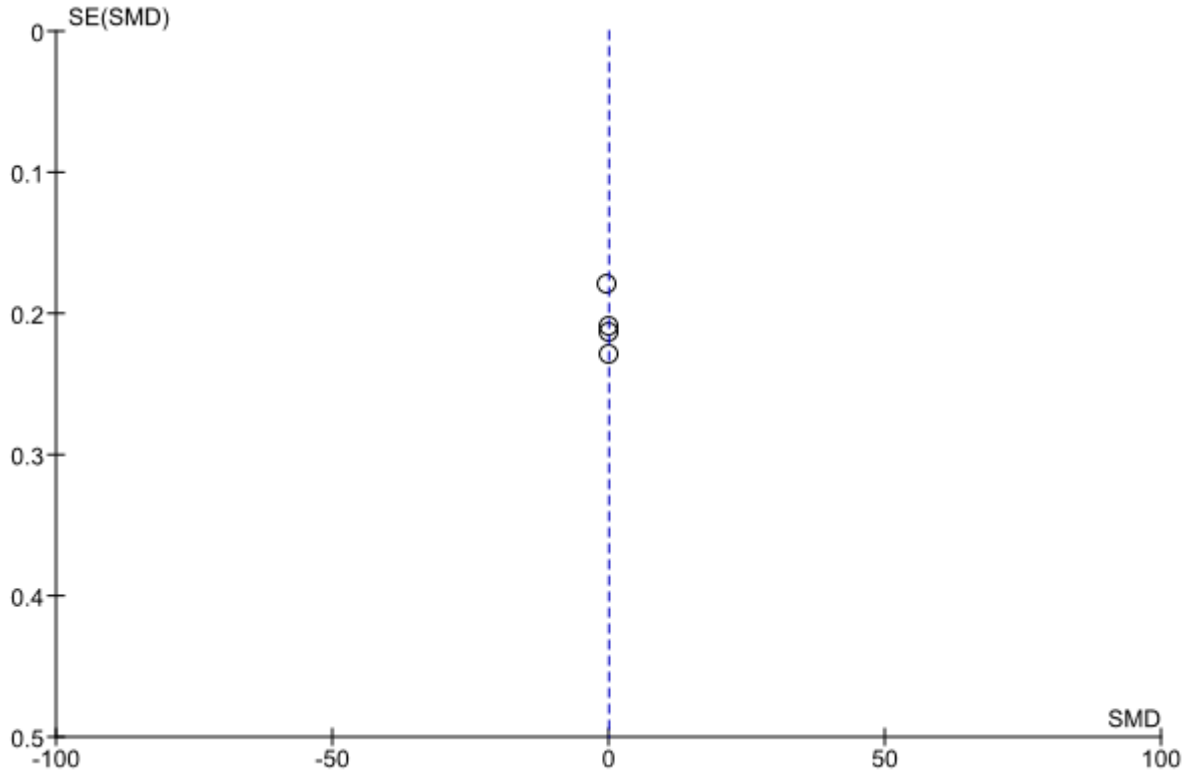
Outcome 3: Mortality



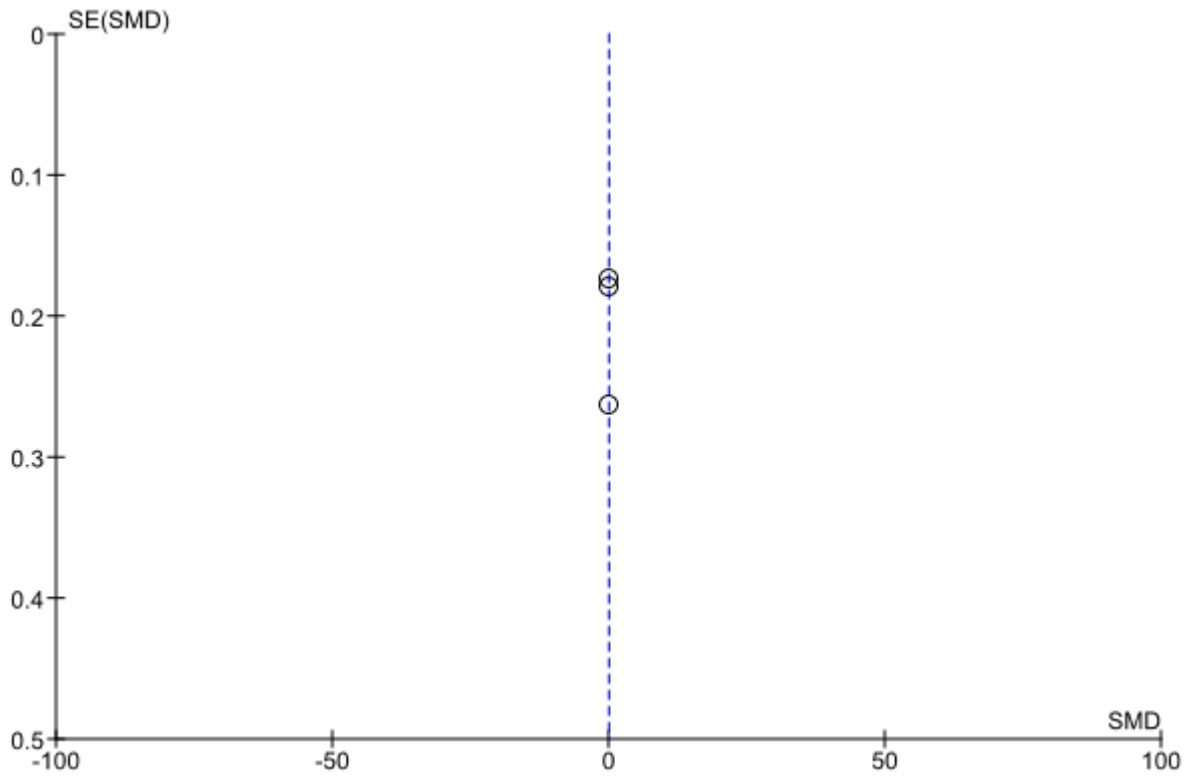
Outcome 4: Patient quality of life



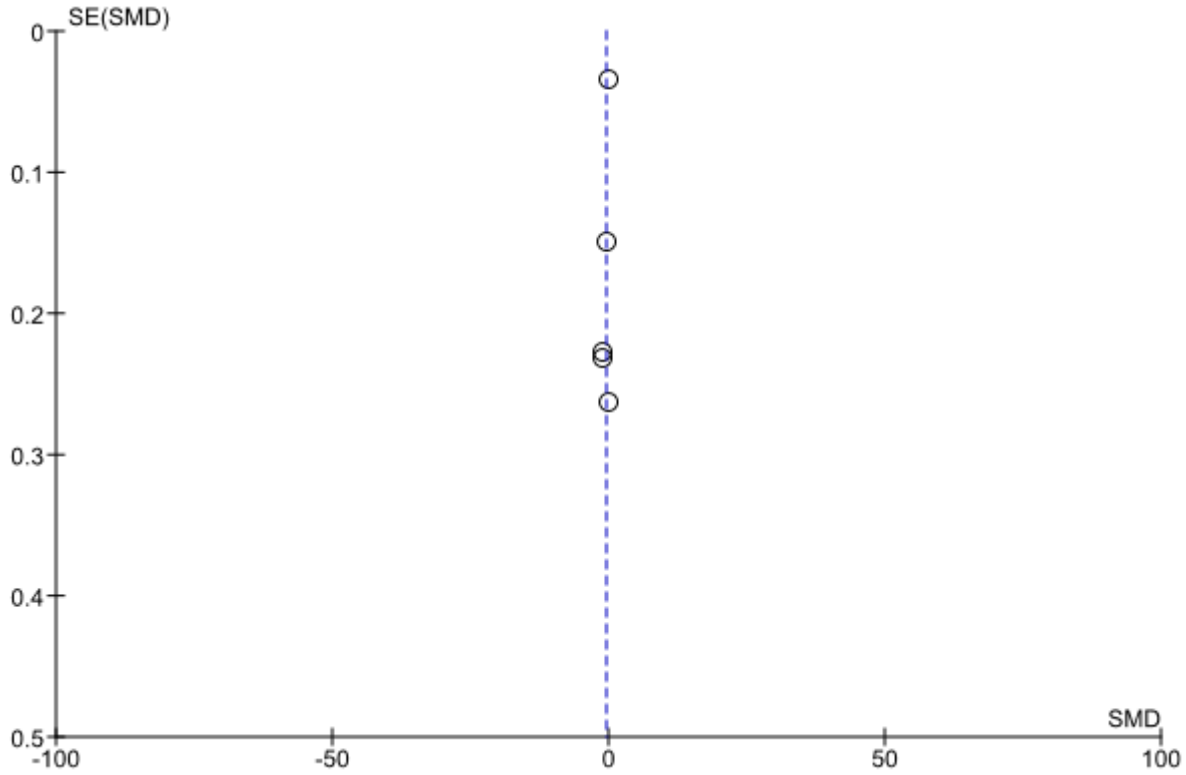
Outcome 5: Patient cognition



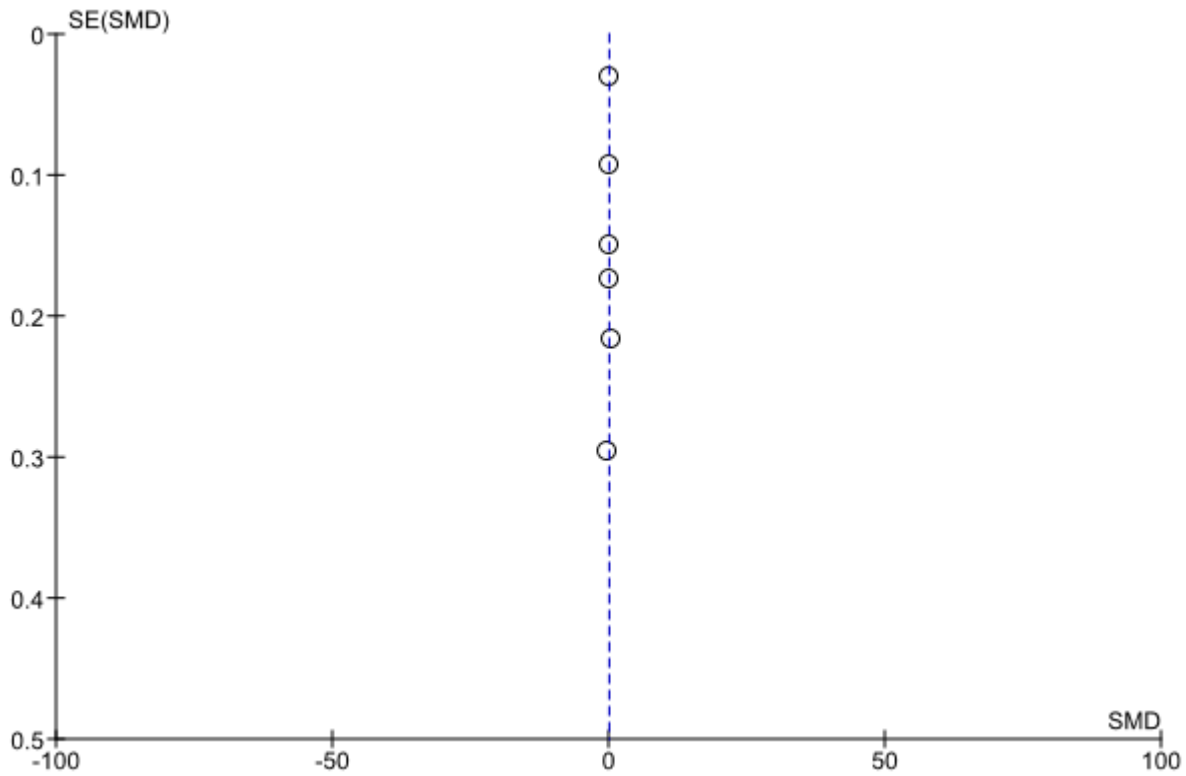
Outcome 6: Patient function



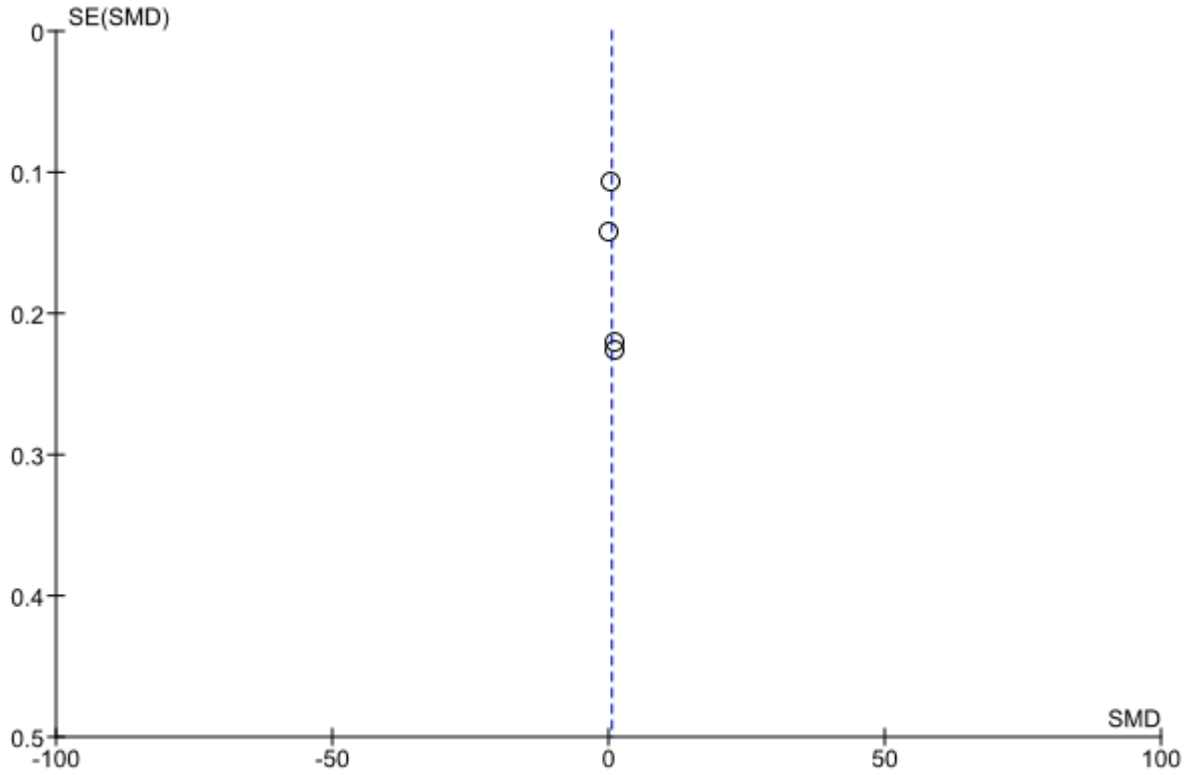
Outcome 7: Caregiver burden



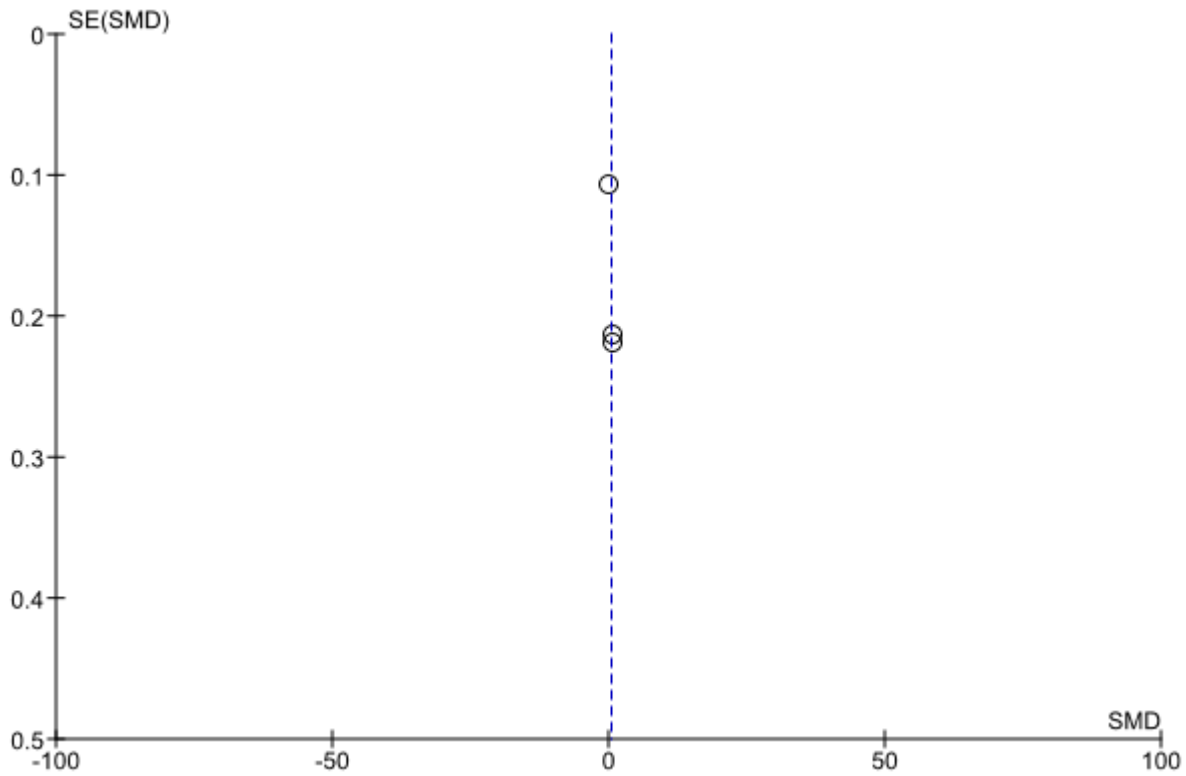
Outcome 8: Caregiver mood



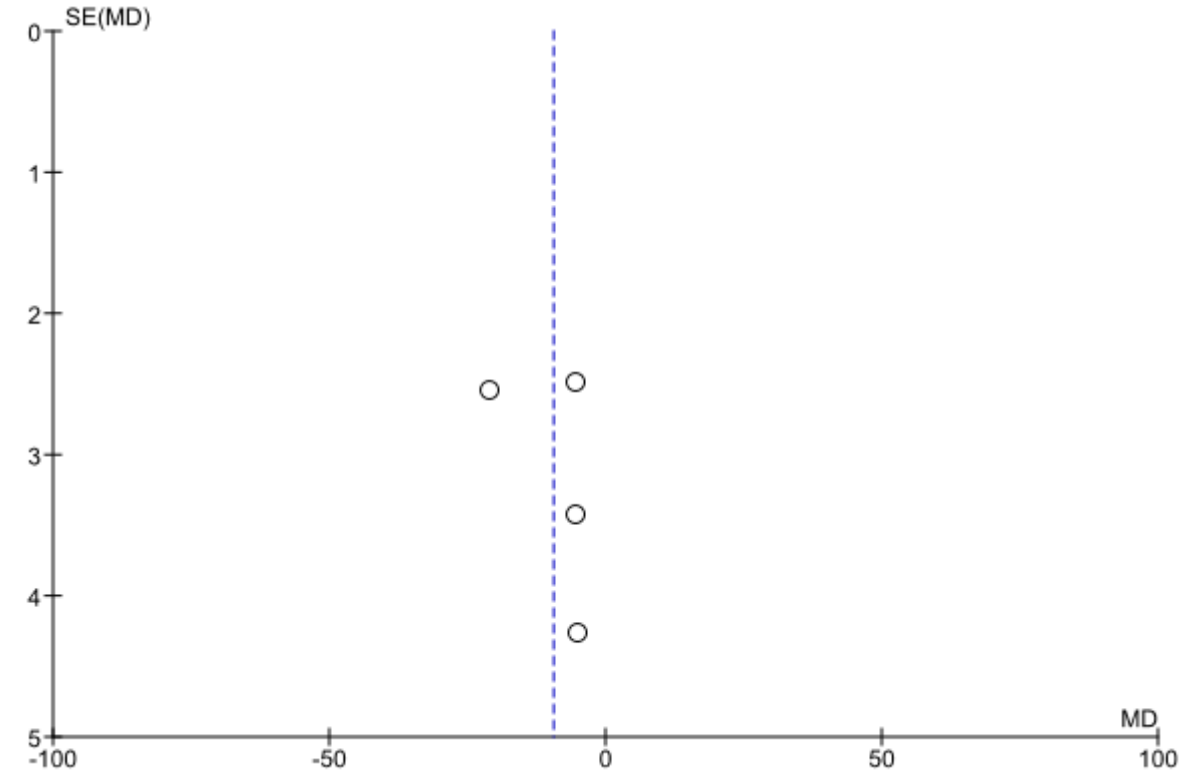
Outcome 9: Caregiver quality of life



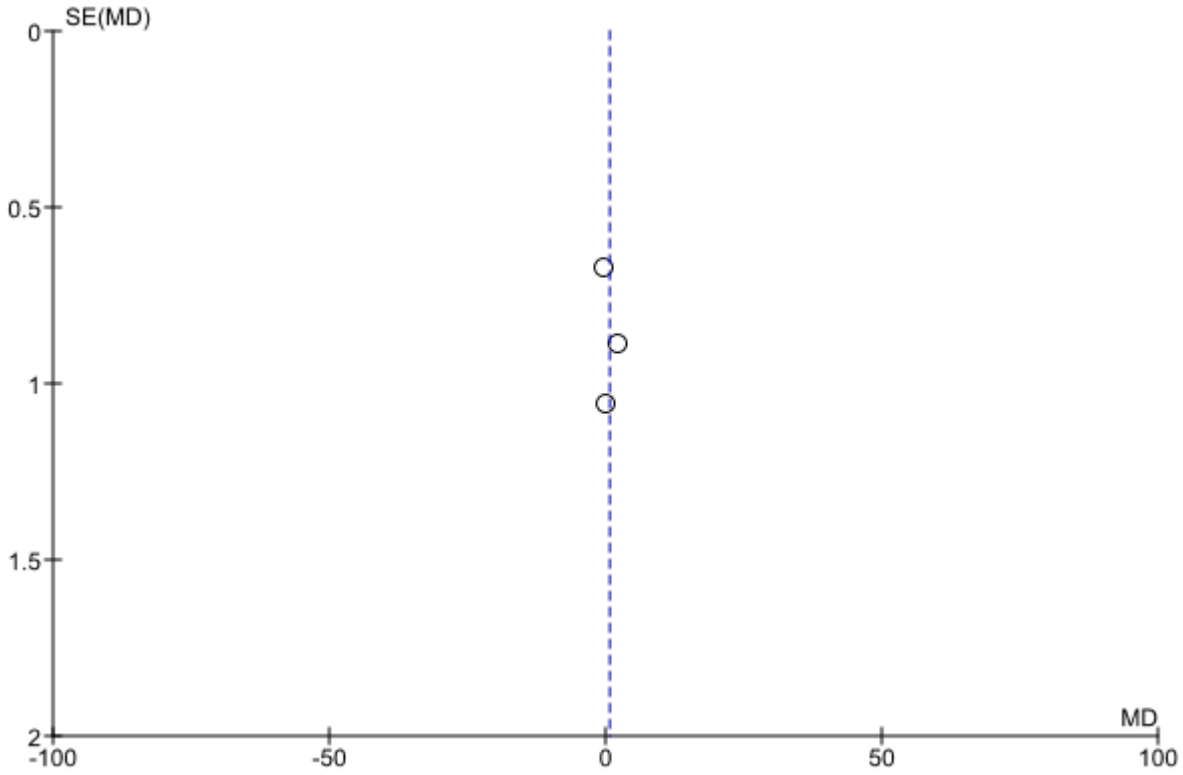
Outcome 10: Social support



Outcome 11: Patient behaviour



Outcome 12: Patient depression



Appendix 8: Interview strategy and topic guides for qualitative study

Views and opinions on a coordinating care services for people with dementia living at home

1. Set the context and explain the purpose of the study

AIMS: To provide the participant with an overall introduction to the study and the general context of the interview.

2. Elicit background and develop narrative

AIMS: To gain some insight into the background of the participant and their experience of community based care in dementia.

3. Focus on the benefits and challenges of the proposed model

AIMS: To identify the participants' perspectives of the benefits of having an intervention that coordinates care in community settings, and also their perspectives of potential challenges of the intervention. In detail, explore the views on specific components of the intervention and what might/ might not work well in addressing the needs of individuals with dementia and their families.

4. Potential modifications to the model

AIMS: To investigate possible ways the intervention model may be improved. This may be to address unmet needs of service users, or to address potential implementation issues raised by professionals.

TOPIC GUIDES

Topic	***Service User Focus***	***Professional Stakeholders Focus***
Background	• Experience of community care • Views on current services	• Experience of community care • Views on current services
Coordinating Services	• Experience of service coordination • Views on need for service coordination	• Experience of service coordination • Views on need for service coordination
Acceptability	• Needs of the dementia population in the community • Outcomes effected by coordinated services	• Current services and integration of new interventions • Existing roles and services relating to new intervention • Implementation issues • Appropriateness of professionals involved
Potential benefits	• Positive components of proposed model • Needs addressed by proposed model	• Positive components of proposed model • Potential benefits to services, and health and social care staff
Potential gaps	• Gaps in proposed model • Needs of service users not addressed in proposed model	• Gaps in proposed model • Needs professionals not addressed in proposed model
Modifications to model	• Suggested improvements to address these needs	• Suggested improvements to address these needs

Appendix 9: Information sheet for service users and information sheet for professional participants

Information sheet for service users

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part we thank you for considering our request.

What is the aim of the project?

This study is part of a larger project that aims to develop a community-based care process that coordinates services for people with dementia who are living at home. The purpose of this study is to explore the views and opinions of individuals involved in dementia care on coordinating services by assigning individuals with dementia a healthcare professional who becomes responsible for managing their care. We want to understand if providing this type of care will meet the needs of individuals with dementia and their families, and if it can improve their wellbeing and health.

Who are we looking for?

We would like to hear from people who have had experience of dementia care services in the community, including individuals with dementia, and their informal caregivers and family members.

What will participants be asked to do?

You will be asked to take part in an interview with a member of the University research team. The interview will last around 30 minutes and will take place in a location most suitable to yourself; this can be at your home or in a private room at the University campus. Your interview will be audio-record for later analysis. If needed, your interview can be split into shorter sessions, for example two 15 minute interviews.

We will begin the interview by asking you questions about your experience with dementia care services. We will then talk about the description of the care service provided, and we will discuss how this might be helpful to individuals with dementia living at home. We will discuss the positive and negative aspects of this type of care, and what could be done to improve the care service.

Do I have to take part?

No – it is entirely up to you. If you decide that you would like to take part, you will be asked to sign a consent form and will be given a copy to keep. You are free to withdraw from the study at any time without giving reason and with no disadvantage to yourself of any kind. If you decide not to take part, the research team will be understanding in respecting your decision and will not contact you again.

What are the potential risks and benefits to taking part?

We do not anticipate any potential risks to your health through taking part in this study. Some of the topics that will be discussed may be sensitive, but it is unlikely to cause any distress. In the unlikely event of distress, we will offer a break or an end to the interview immediately.

There are great benefits to taking part in research studies. By taking part in this study, you will contribute in the attempts to improve community care for the dementia population.

Should you feel the University campus is a more comfortable place for you to attend the interview, your travel to and from the campus will be reimbursed.

What about privacy and confidentiality?

All of the information that is collected in the study will be kept strictly confidential. Electronic information will be kept on a secure, password protected PC and hard copies will be stored in a locked filing cabinet, with only the research team having access. All of the interview records will be anonymised so will contain no personal identifying information.

What will be made of the information I provide?

Interviews will be recorded and the content will be analysed to identify ways that we can improve the care service to make it more suitable for individuals with dementia and their families.

The results of the study will form part of a PhD project, and will be published. Although these may include quotes from the interviews provided, personal identification details will not be revealed. We are also able to send you a report on the summary of findings from the study.

What if participants have any questions?

If you have any questions about our project, either now or in the future, please feel free to contact either:

Amy Backhouse

Lead Researcher and PhD Student

Medicine

Tel: 01392 725272

A.Backhouse@exeter.ac.uk

Prof. Chris Dickens

Professor in Psychological

Tel: 01392 726017

C.M.Dickens@exeter.ac.uk

Thank you for taking the time to read through this information sheet and considering taking part in our research study.

Complaints

If you have any complaints about the way in which this study has been carried out please contact the Co-chairs of the University of Exeter Medical School Research Ethics Committee:-

Ruth Garside, PhD

Chair of the UEMS Research Ethics Committee

Email: uemsethics@exeter.ac.uk

Information sheet for professionals

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part we thank you for considering our request.

What is the aim of the project?

This study is part of a larger project that aims to develop a community-based intervention that coordinates care for people with dementia. The purpose of this study is to explore the views and opinions of individuals involved in dementia care on coordinating services by assigning individuals with dementia a professional who becomes responsible for managing all aspects of care. We want to understand if providing this type of care will meet the needs of individuals with dementia and their families. But additionally, if the care is acceptable and feasible to health and social care staff, and what is the likelihood for successful implementation.

Who are we looking for?

We would like to hear from health and social care professionals who have had experiences and roles in community-based dementia care. This may be individuals with previous experience is case management roles, or interventions that have aimed to coordinate care. We would like to include a broad range of perspectives, so please get in tough should you feel you would like to contribute your experiences. .

What will participants be asked to do?

You will be asked to take part in an interview with a member of the University research team. The interview will last around 30 minutes and will take place in a location most suitable to yourself; this can be at your place of work, home or in a private room at the University campus. Your interview will be audio-record for later analysis. If needed, your interview can be split into shorter sessions, for example two 15 minute interviews.

We will begin the interview by asking you questions about your experience in dementia care services or coordinating interventions. We will then talk about the description of the new intervention, and we will discuss the positive and negative aspects of the care service, and issues surrounding implementation in current health and social care services.

Do I have to take part?

No – it is entirely up to you. If you decide that you would like to take part, you will be asked to sign a consent form and will be given a copy to keep. You are free to withdraw from the study at any time without giving reason and with no disadvantage to yourself of any kind. If you decide not to take part, the research team will be understanding in respecting your decision and will not contact you again.

What are the potential risks and benefits to taking part?

We do not anticipate any potential risks to your health through taking part in this study. Some of the topics that will be discussed may be sensitive, but it is unlikely to cause any distress. In the unlikely event of distress, we will offer a break or an end to the interview immediately.

There are great benefits to taking part in research studies. By taking part in this study, you will contribute in the attempts to improve community care for the dementia population.

Should you feel the University campus is a more comfortable place for you to attend the interview, your travel to and from the campus will be reimbursed.

What about privacy and confidentiality?

All of the information that is collected in the study will be kept strictly confidential. Electronic information will be kept on a secure, password protected PC and hard copies will be stored in a locked filing cabinet, with only the research team having access. All of the interview records will be anonymised, so will contain no personal identifying information.

What will be made of the information I provide?

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The results of the study will form part of a PhD project, and will be published. Although these may include quotes from the interviews provided, personal identification details will not be revealed. We are also able to send you a report on the summary of findings from the study.

What if participants have any questions?

If you have any questions about our project, either now or in the future, please feel free to contact either:

Amy Backhouse

Lead Researcher and PhD Student

Medicine

Tel: 01392 725272

A.Backhouse@exeter.ac.uk

Prof. Chris Dickens

Professor in Psychological

Tel: 01392 726017

C.M.Dickens@exeter.ac.uk

Thank you for taking the time to read through this information sheet and considering taking part in our research study.

Complaints

If you have any complaints about the way in which this study has been carried out please contact the Co-chairs of the University of Exeter Medical School Research Ethics Committee:-

Ruth Garside, PhD

Chair of the UEMS Research Ethics Committee

Email: uemsethics@exeter.ac.uk

Appendix 10: Consent forms for all participants in qualitative study

Views and opinions on a care coordinating service for people with dementia living at home

CONSENT FORM FOR PARTICIPANTS

VERSION NUMBER [1.1] : DATE [01.08.2016]

I have read the Information Sheet Version Number [1.1] Dated [01.08.2016] concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

1.	My participation in the project is entirely voluntary;	Y/N
2.	I am free to withdraw from the project at any time without any disadvantage;	Y/N
3.	The information [*audio tapes and transcripts*] will be retained in secure storage	Y/N
4.	I will be asked some questions that are not pre-set and will depend on how the interview develops	Y/N
6.	The results of the project may be published but my anonymity will be preserved	Y/N

I agree to take part in this project.

.....	……..	.....
(Printed name of participant)	(Signature of participant)	(Date)
.....	……..	.....
(Printed name of researcher)	(Signature of researcher)	(Date)

This project has been reviewed and approved by the University of Exeter Medical School Research Ethics Committee

UEMS REC REFERENCE NUMBER: *(TO BE INSERTED ONCE ETHICAL APPROVAL HAS BEEN GRANTED)*

Appendix 11: Contact information sheet for all participants in the qualitative study

STUDY: A qualitative study of service user and health care professional's views of a community based intervention coordinating care in dementia

Name …….....

(Please print name)

Address .....

.....

.....

Telephone contact details ……...

Email address .....

Appendix 12: Case report form for participants in the qualitative study with a diagnosis of dementia

A qualitative study of service user and health care professional's views of a community based intervention coordinating care in dementia

CASE REPORT FORM

Recruitment Number: ___ ___ ___ ___ ___ ___

Consent

Has the participant given consent?	Yes ☐	No ☐

1. Sociodemographic Information

Date of Birth: __ __ / __ __ / __ __ __ __ **Gender:** Male ☐ Female ☐

Marital Status:

- Single ☐
- Married/ partnership ☐
- Separated ☐
- Divorced ☐
- Widowed ☐
- Not known ☐

Ethnic Group:

White: British ☐
White: Irish ☐
White: Other ☐
White & Asian ☐
White & Black Caribbean ☐
White & Black African ☐
Mixed: Other ☐
Asian: Indian ☐
Asian: Pakistani ☐
Asian: Bangladeshi ☐
Asian: Other ☐
Black or Black British ☐
Black: Caribbean ☐
Black: African ☐
Black Other ☐
Chinese ☐
Other ☐
Prefer not to say/ Not disclosed ☐

2. Education and Employment

Level of education:

No qualifications ☐
GCSE's/ O'levels ☐
AS/ A-levels ☐
NVQ or other vocational qualification ☐
Undergraduate degree ☐
Postgraduate degree ☐
Doctoral degree ☐
Professional degree (e.g. MD) ☐

Employment: Retired ☐ Employed ☐ Unemployed ☐

Professional background or trade: ……
……
……

3. Diagnosis

Diagnosis type: ……..

Diagnosis date (estimate): ..……

4. <u>Services Used</u>

Name of services used:……...
……
……
……
……

Number of times accessed:……

A qualitative study of service user and health care professional's views of a community based intervention coordinating care in dementia

CASE REPORT FORM

Recruitment Number: ___ ___ ___ ___ ___ ___

Consent

Has the participant given consent?	Yes ☐	No ☐

1. Sociodemographic Information

Date of Birth: __ __ / __ __ / __ __ __ __ **Gender:** Male ☐ Female ☐

Marital Status:

- Single ☐
- Married/ partnership ☐
- Separated ☐
- Divorced ☐
- Widowed ☐
- Not known ☐

Ethnic Group:

White: British	☐	Asian: Bangladeshi	☐
White: Irish	☐	Asian: Other	☐
White: Other	☐	Black or Black British	☐
White & Asian	☐	Black: Caribbean	☐
White & Black Caribbean	☐	Black: African	☐
White & Black African	☐	Black Other	☐
Mixed: Other	☐	Chinese	☐
Asian: Indian	☐	Other	☐
Asian: Pakistani	☐	Prefer not to say/ Not disclosed	☐

2. Education and Employment

Level of education:

No qualifications	☐
GCSE's/ O'levels	☐
AS/ A-levels	☐
NVQ or other vocational qualification	☐
Undergraduate degree	☐
Postgraduate degree	☐
Doctoral degree	☐
Professional degree (e.g. MD)	☐

Employment: Retired ☐ Employed ☐ Unemployed ☐

Professional background or trade: ……
……
……

3. Caring Relationship

Relationship to individual with dementia: ……

Live with individual with dementia: Yes ☐ No ☐

Primary caregiver: Yes ☐ No ☐

Hours of caregiving per day (estimate): ……

4. Services Used

Name of services used:……...
……
……
……
……

Number of times accessed:……

A qualitative study of service user and health care professional's views of a community based intervention coordinating care in dementia

CASE REPORT FORM

Recruitment Number: ___ ___ ___ ___ ___ ___

Consent

Has the participant given consent?	Yes ☐	No ☐

1. Sociodemographic Information

Date of Birth: __ __ / __ __ / __ __ __ __ **Gender:** Male ☐ Female ☐

Marital Status:

- Single ☐
- Married/ partnership ☐
- Separated ☐
- Divorced ☐
- Widowed ☐
- Not known ☐

Ethnic Group:

White: British	☐	Asian: Bangladeshi	☐
White: Irish	☐	Asian: Other	☐
White: Other	☐	Black or Black British	☐
White & Asian	☐	Black: Caribbean	☐
White & Black Caribbean	☐	Black: African	☐
White & Black African	☐	Black Other	☐
Mixed: Other	☐	Chinese	☐
Asian: Indian	☐	Other	☐
Asian: Pakistani	☐	Prefer not to say/ Not disclosed	☐

2. Education and Employment

Level of education:

No qualifications	☐
GCSE's/ O'levels	☐
AS/ A-levels	☐
NVQ or other vocational qualification	☐
Undergraduate degree	☐
Postgraduate degree	☐
Doctoral degree	☐
Professional degree (e.g. MD)	☐

Employment: Retired ☐ Employed ☐ Unemployed ☐

Professional background: ……

……

……

Employer: ……..

Job title: ……..

Number of years in role: ……

Number of years working in dementia care: ……

Prior relevant roles: ……

Appendix 15: Ethics form approved by the University of Exeter Medical School Ethics Committee

To save replication of documents, the appendices have been removed from the ethics form as they are part of the thesis appendices

UNIVERSITY OF EXETER MEDICAL SCHOOL

RESEARCH ETHICS COMMITTEE

APPLICATION FORM

FOR

RESEARCH ETHICS APPROVAL

Name of Applicant:	Amy Backhouse
Project Title:	A qualitative study of service user and health care professionals views of a community based intervention coordinating care in dementia
Date:	20/07/2016
Version Number: *(1 for first time applications)*	1
Application Number: (For Ethics Committee use only)	

SECTION A: GENERAL

1 Title of the Study:	A qualitative study of service user and health care professionals views of a community based intervention coordinating care in dementia		
Project Start Date:	09/2016	Project End Date:	06/2017

2 Full name of applicant: Amy Backhouse					
Position Held:	PhD Student at PenCLAHRC				
Institution:	University of Exeter Medical School	Course Title (if student):	N/A		
Location:	College House, St Luke's Campus, Heavitree, Exeter EX1 2LU				
Email:	A.backhouse@exeter.ac.uk	Telephone:	01392 725272	Fax:	
Please provide details of any and all other researcher(s) who will work on the research project: (if more than three researchers please extend table as appropriate)					
Name(s):	Professor Chris Dickens				
Position Held:	Professor of Psychological Medicine				
Location:	College House, St Luke's Campus, Heavitree, Exeter EX1 2LU				
Contact details (e-mail/ telephone/fax):	C.M.Dickens@exeter.ac.uk/ 01392 726017				
Name(s):	Professor David Richards				
Position Held:	Professor in Mental Health Services Research				
Location:	South Cloisters, St Luke's Campus, Heavitree, Exeter EX1 2LU				
Contact details (e-mail/ telephone/fax):	D.A.Richards@exeter.ac.uk / 01392 724615				
Name(s):	Professor Rose McCabe				
Position Held:	Professor of Clinical Communication				
Location:	College House, St Luke's Campus, Heavitree, Exeter EX1 2LU				
Contact details (e-mail/ telephone/fax):	C.McCabe@exeter.ac.uk / 01392 725950				

3 Is this proposal part of a PhD?	Yes	X	No	

If yes, please complete the remainder of this section.			
Year of Study:	Second Year		
Name of Primary Supervisor/Director of Studies:	Professor Chris Dickens	Position held:	Professor of Psychological Medicine
Location:	College House, St Luke's Campus, Heavitree, Exeter EX1 2LU		
Contact details (email/telephone/fax):	C.M.Dickens@exeter.ac.uk/ 01392 726017		
Name of Second Supervisor:	Professor David Richards	Position held:	Professor in Mental Health Services Research
Location:	South Cloisters, St Luke's Campus, Heavitree, Exeter EX1 2LU		
Contact details (email/telephone/fax):	D.A.Richards@exeter.ac.uk / 01392 724615		

4 Declaration to be signed by the Applicant or the supervisor in the case of a student:

- I confirm that the research will be undertaken in accordance with the University Ethical Framework, Good Research Practice Policy, and Code of Research Ethics.
- I will undertake to report formally to the relevant University Research Ethics Committee for continuing review approval.
- I shall ensure that any changes in approved research protocols are reported promptly for approval by the relevant University Ethics committee.
- I shall ensure that the research study complies with the appropriate regulations and relevant University of Exeter policies on the use of human material (if applicable) and health and safety.
- I shall ensure that any external permissions necessary for the research to be undertaken are obtained prior to the research taking place.
- I am satisfied that the research study is compliant with the Data Protection Act 1998, and that necessary arrangements have been, or will be, made with regard to the storage and processing of participants' personal information and generally, to ensure confidentiality of such data supplied and generated in the course of the research.

(Note: Where relevant, further advice is available from the University of Exeter Medical Scholo Data Protection Officer).

- I will ensure that all adverse or unforeseen problems arising from the research project are reported in a timely fashion to the Chair of the relevant University Research Ethics Committee.
- I will undertake to provide notification when the study is complete and if it fails to start or is abandoned.
- I have met and advised the student on the ethical aspects of the study design and am satisfied that it complies with the current professional (*where relevant),* School and University guidelines.
- I have read this application and believe it to be scientifically and ethically sound

Signature of Applicant: **Date: 30/08/16**

Signature of Supervisor: **Date: 30/8/2016**

Departmental Approval

- I give my consent for the application to be forwarded to the University of Exeter Medical School Research Ethics Committee with my recommendation that it be approved.
- I confirm that this submission has been appropriately peer reviewed.

Signature of Head of Research Institute/Centre or Vice Dean (Education) (or approved nominee)

Signature: **Date: 1st September 2016**

Printed Name: Professor Stuart Logan

5 Name and affiliation of Peer Reviewer(s)			
Name:	Darren Moore	Position held:	Research Fellow
Institution:	University of Exeter Medical School		
Contact details (email/telephone/fax):	d.moore@exeter.ac.uk 01392 727405		

SECTION B: FUNDING

6 If the research is externally funded, what is the source of the funding?				
N/A				
6.1 What is the value of the grant?				
6.2 Are there any conditions attached to the funding which could have an impact on this application?				
YES		NO		
If yes, please specify.				

SECTION C: THE RESEARCH

7 In lay terms, please provide an outline of the proposed research, including:

- background
- objectives / hypothesis
- research methodology
- contribution of research
- justification of benefit
- be specific about focus groups
- state whether this is forming part of a PhD

(*max 1000 words).*

A number of recent reports [1, 2] state that although there are a variety of services in place to support community-based individuals living with dementia and their families, it is difficult to access and navigate these services. One approach taken to improve the management of care provided to the dementia population is the allocation of a health or social care professional to take responsibility for coordinating all aspects of care for the individual. The primary focus is on developing a collaborative process of planning, facilitating and coordinating care, and providing proactive support for both the individual with dementia and their informal caregiver(s).

These models of care are complex and diverse in nature, and are often differ in aspects like target population, intervention characteristics and contextual factors. To create a successful and cost-effective care model it is important to understand the individual components and how they are will work together most efficiently.

A mixed studies systematic review was conducted to identify these key components. The review firstly evaluated stakeholders views of community based interventions coordinating care in dementia, identifying components within the interventions that were valued by stakeholders. These components were then mapped onto trials of coordinating interventions to see if they showed an association with effects. The results of the review have been used to develop a care model that aims to coordinate services for individuals diagnosed with dementia who are living at home. We feel it is now important to evaluate the model by returning to relevant stakeholders including service users and health care professionals to investigate perspectives on appropriateness and acceptability of the model, as well as issues around implementation.

<u>Research Aims:</u>

To investigate stakeholders' perspectives on the care model; in particular, to evaluate the perceived acceptability, value and potential issues relating to implementation.

The proposed study will involve semi-structured interviews with various stakeholder group including individuals with dementia, informal caregivers, and health and social care professionals with experience in dementia care and/or care coordination interventions. Interviewees will be identified through various resources including current University networks, the Join Dementia Research database and existing contacts of the lead

researcher/ supervisors. The recruitment will follow a standard procedure including participant information sheets to ensure the aims of the study are clear before participation and signing the study consent forms.

The interviews will focus on discussion around the care model that aims to coordinate services for individuals with dementia and their families. Interviewees will be presented with a simple depiction of the model including a clear aim and descriptions of each component. An interview topic guide and strategy has been developed to aid discussion around the model, and are based upon findings from the review and the lead researcher's prior training in qualitative interviews.

The lead researcher will conduct the interviews which will be audio recorded and transcribed verbatim. Data will be managed in using specialised qualitative data analysis software (Nvivo11), and analysed using a thematic analysis approach. This approach will allow us to link our findings back to the review evidence found in phase one, and also build on the new evidence emerging from interview responses. The care model will be modified in response to the interview findings. We will take an iterative approach to this process, beginning analysis as data is collected and making modifications to the care model and interview topic guide as results emerge. Any modifications will be recorded and reported in final write-up.

Field notes will be taken by the researcher will also be used throughout the interviewing process. These notes will contain details on researcher observations, and nonverbal expressions and gestures of participants to allow for a more detailed description of the interaction. Field notes will add transparency to the data and process of analysis.

Taking a qualitative approach to the research question has both strengths and limitations. Qualitative interviews will allow rich, detailed data to be collected from individuals with various relevant experiences in dementia care. With this type of approach and data the context and social themes surrounding dementia services and care can be taken into account. However, a qualitative approach does not allow for an objective comparison that would be present with quantitative research, and has comparatively smaller sample sizes. With this particular study, the methods may have difficulty in finding a consensus on the care model as qualitative data is often unique to individuals and can be difficult to generalise.

Include any questionnaires, psychological tests, etc. at the end of your application.

8 Location of study

8.1 Where will the study take place?

Interviews will take place in a location of the participant's choice. The most convenient and safe places for service users are likely to be the participants home or a private room at the University. Health and social care professionals may have the added options of their work place, either in shared worked space or a booked room.

8.2 If the study is to be carried out overseas, what steps have been taken to secure research and ethical permission in the country of study? (Please attach evidence of approval if available.)

N/A

9 Multi-centre and off-campus studies

If this is a multi-centre or off-campus study, please answer the appropriate questions below; otherwise, go to Question 11.

9.1 Does this project involve a consortium (other research partner organisations)?

YES		NO	X	

If yes, please complete the details below in Question 9.2.

9.2 Who has overall responsibility for the study?

N/A

Please provide details of the contractual agreement between UEMS and the other organisation(s).

9.3 Is this an off-campus study?

YES	X	NO		

If yes, please provide signed, written permission from an appropriate level of management within the relevant organisation(s).

UEMS ethical approval has been sought first before approaching stakeholder groups through various routes. For professionals employed by the NHS, written permission will be sought from their local Trust before conducting interview(s). Likewise, if the professional is employed by an external organisation, written permission will be sought before conducting the interview.

10 Has approval been sought from other Ethics Committees and LRECs?

YES		NO	X	

Please enclose copies of approval letters, where applicable.

11 Who will have overall control of the data generated?

Amy Backhouse – lead researcher

Professor Chris Dickens – First Supervisor

12 How do you propose to disseminate the results of your research?

The study is part of a broader PhD project that aims to develop a community-based intervention that coordinates care in dementia, and will therefore form part of the thesis that will be openly available upon completion.

The study will be written up in the form of an academic paper and submitted for publication to an appropriate journal (e.g. *Age & Ageing* or *BMC Health Services Research*). Furthermore, the results of the study will be disseminated through conference presentations and posters, and other suitable research events (e.g. seminars).

A summary of the research findings will be sent to participants who have expressed an interest in receiving further information.

13 METHODS AND PROCEDURES

Describe the nature of the task required of participants and the various precautionary measures to be taken to avoid harm or discomfort if appropriate. If the study is likely to cause discomfort or distress to subjects, estimate the degree and likelihood of discomfort or distress.

(Include a copy of any questionnaire / survey form to be used at the end of your application)

Interviews

Semi-structured, face-to-face interviews will be conducted in a private setting. A topic guide has been developed to focus on the care model, but the questions will be flexible, open-ended and broad to explore issues surrounding the model in greater depth and detail. Interviews will last approximately 30 minutes. We feel this is a sufficient length to cover the topics required and for participants to make significant data contribution. Furthermore, we feel this is a reasonable length to ask of participants to be involved in detailed discussion.

Informed Consent

Prior to the interview, participants will be sent three things to look over; an information sheet, consent form and a simple description of the care model to be discussed in the

interview. This will include a pictorial depiction of the model as well as a brief description of each component and how they will work together to coordinate care for individuals with dementia living in the community.

Before the start of the interview, the researcher will give the participant time to ask any questions they had about the information sheet or consent form. They will then go through both the sheet and form in detail to ensure the participant understood each element. All participants will be told about their right to withdraw from the study at any point without a given reason and can refuse to answer questions or continue the course of the interview should they wish. Participants will be informed that the nature of the interview is open-ended by which the course of the interview will develop in response to the answers given.

Participants will be asked to sign the consent form if they are happy with the contents and are happy to be involved. The researcher will ensure that the consent given by asked participant is fully informed and voluntary. After the interview, participants will be as if they were happy with the interview and if there was anything they did not want included in their final data transcript.

Should the interview be split over a number of sessions, verbal (and audio recorded) consent will be confirmed at the start of each session. This will be less burdensome for participants than taking written informed consent in each session.

Care Model for Discussion

The care model for discussion will be based on the results from a mixed-studies review looking at the views of stakeholders on key components of interventions coordinating care in dementia, followed by analysis to investigate if these components were associated with effects in RCTs.

The model will describe individuals involved in the intervention, which will be centred on a case manager and the individuals with dementia and their informal caregiver. The model will describe how the case manager will coordinate care, and the types of tasks they will carry out including assessments, care plans and referrals. The model will also describe how the case manage will collaborate with broader parties in primary care, including the General Practitioner (GP), secondary care services and community-based services in order to facilitate care an meet all needs identified.

Questioning and Strategy

The interviews will be semi-structured, with a pre-determined topic guide. The questions will be open-ended to elicit a discussion around the model of care. The interview strategy will be aimed at making the participants feel at ease and comfortable to facilitate a natural discussion.

The questioning to interviewees may take different form, and topic guides will develop in response to previous interviews. Interviews with service users will be focused around the needs of individuals with dementia and informal caregivers who are living at home, and

will facilitate discussion around how case managers can provide maximum support and coordinate services for users. Interviews with health and social care professionals will be focused around the practicality and implementation issues in trying to meet the needs of service users through the use of the care model.

Risk

We do not anticipate a situation in which a participant will become distressed or express any feelings/behaviour that would indicate they were a risk to themselves or others. However, in the unlikely event that the researcher feels that an assessment is required, a standard protocol for risk management will followed. This will involve conducting a risk assessment and where a risk is detected, the most appropriate action will take place.

The interview will initially be paused to give the participant and researcher time to address the situation, and see if the participant wishes to continue. If either party feels that the interview should not continue, then it will be ended permanently. The researcher will complete the risk assessment if they feel it necessary, and where appropriate the carer will be informed of results. The researcher will aim to support the participant in the most appropriate way possible, and will have a sound knowledge of available services to which they can refer the participant if necessary.

The lead researcher conducting the interviews has Mood Disorders Centre (MDC) risk assessment raining, and relevant experience in following risk management protocols for adverse events.

Analysis

All interviews will be recorded and transcribed verbatim, and these transcripts will be the data for analysis. Nvivo11 will be used to manage data and support analysis.

Data analysis will follow thematic analysis method[3] that will allow for the use of both inductive reasoning from interview responses and deductive reasoning, linking with the phase one evidence review. The care model will be modified in response to the analysis findings. An iterative approach will be taken to this process, beginning analysis as data is collected and making modifications to the interview topic guide and model as results emerge. Any modifications will be recorded and reported in final write-up.

Provisional Timetable for Study

The proposed study will take approximately 8 months to complete. The project stages are outlined below:

1. Recruitment (see section 26. and 27.)
2. If recruitment is successful, the interviews will take place over 2 to 3 months: beginning of December 2016 to February 2017

3. The transcription and analysis of audio recordings will begin during the interview stage, and will take place across December 2016 to April 2017. This will be an iterative process of refining the model of care.
4. The model of a community based intervention coordinating care in dementia will be finalised and the formal study will be written up into an academic paper over subsequent months by June 2017.

Lone Worker Policy

As this study will involve one researcher likely to be working away from the University and visiting participants at various locations, lone worker guidance will be required. Prior to commencing any field work, a lone worker risk assessment will be conducted to identify potential risks and hazards, and a full lone worker procedure addressing identified risks will be put in place. The procedure will include a lone worker 'buddy' who is used for a check in and check out contact, to ensure the safety of the researcher.

Should the researcher fail to report to the 'buddy' within two hours of the start of the interviewer, the 'buddy' and/or supervisor will be responsible for calling the researcher with aim of making contact. If they are unable to make contact with the researcher, then the 'buddy' and/or supervisor will be responsible for contacting their Next of Kin who will be detailed on the lone worker form.

13.1 Does the study include any of the following interventions / invasive procedures?

	YES	NO		YES	NO
Participant-observation / non participant-observation	☐	☒	Self-completion questionnaires	☐	☒
Interviews	☒	☐	Video / audio recording	☒	☐
Focus Groups	☐	☒	Administration of substance / drug (e.g. caffeine / doubly labeled water etc)	☐	☒

Physical examination	☐	☒	Manipulation of diet	☐	☒
Arterial puncture*	☐	☒	Venepuncture*	☐	☒
Urine sample*	☐	☒	Fingertip blood sample*	☐	☒
			Saliva sample*	☐	☒
Body Imaging (e.g. MRI, DEXA, X-rays)	☐	☒			
* if yes, will samples be retained for subsequent testing for factors other than described in this proposal?				☐	☐
If yes, will samples be anonymised?				☐	☐

If you are using human tissue in your project, you must complete section E.

14 Products and devices				
14.1 Does the research involve the testing of a product or device?				
YES		NO	X	
If yes, please describe it.				
N/A				
14.2 If this research involves a drug, is it being used in accordance with its licensed uses?				
YES		NO	X	
If no, please explain why:				
N/A				

SECTION D: THE PARTICIPANTS

For the purposes of this section, "participants" include human subjects, their data, their organs and/or tissues. For participants to be recruited to the research, please state:	
15 Number of participants:	18 - 22

16 If data are to be collected on different sites, please state the number of participants at each site:

Site 1:	Tbc	Number of participants:	
Site 2:	Tbc	Number of participants:	

(insert additional sites if necessary)

17 How have you arrived at this number? Please state proposed inclusion/exclusion criteria. If appropriate has the protocol been reviewed by a Statistician?

I will purposively sample between 8-10 service users, who will be individuals with dementia, informal caregivers and family members, and between 10-12 health and social care professionals with a variety of experience and roles in dementia care. In a paper by Mason[4] (2010) discussing sample size and saturation in PhD qualitative interview studies, a guideline of 15 participants is suggested for qualitative research. This guiding figure increases with more complex analyses such ethnography or grounded theory. Although it is difficult to predict a number for theoretical saturation, we expect these numbers for each stakeholder group to give a sufficient range and depth of data[5]. Additionally, these numbers are manageable for the research project and any time constraints. The data will not be under-analysed as to ensure full saturation and that the participants' time has been well used.

The purposive sampling of stakeholders will be based on maximum variation sampling as we are interested in capturing a wide range of perspectives[6]. Participants will be selected to vary on

characteristics such as; age, gender, relationship to individual with dementia or employment responsibilities in dementia care.						
18 Age group or range *(e.g., under 60s*):		Not specified				
18.1 Sex:	Male	-		Female	-	
19. Is this a single sex study?						
	YES		**NO**	X		
If yes, please justify the reason(s) for gender selection						
While some studies explicitly focus on gender specific experiences, care should be taken to ensure that women or men are not unnecessarily excluded from participating in research.						

20 Do participants belong to any of the following vulnerable groups?					
Children:	**YES**		**NO**	X	
Participants unable to give informed consent in their own right *(e.g., people with learning difficulty)*:					
	YES		**NO**	X	
Other vulnerable groups (please specify)					
	YES	X (older adults with a diagnosis of demented)	**NO**		

Care will need to be taken to formulate inclusion/exclusion criteria that clearly justify why certain individuals are to be excluded, to avoid giving the impression of unnecessary discrimination. On the other hand, the need to conduct research in "special" or "vulnerable" groups should be justified and it needs generally to be shown that the data required could not be obtained from any other class of participant.

If the answer to any of the above is yes, please complete Questions 21 to 25; otherwise proceed to Question 26.

21 Please explain why it is necessary to conduct the research in such vulnerable participants and whether required data could be obtained by any other means.

This research forms part of a PhD project that aims to develop a community-based intervention to coordinate care for individuals with dementia. After a reviewing process, a model of the intervention has been developed and it is now essential that the views of individuals with first-hand experience of community dementia care are sought. The input of individuals with dementia is critical to understanding the needs present in the community and how the intervention can be shape to meet these needs. Therefore the views of these individuals are important to further inform the development stages of the intervention.

22 Please state what special or additional arrangements have been made to deal with issues of consent and the procedures to safeguard the interests of such participants.

All participating individuals must be able to give their own voluntary, fully informed consent. The lead researcher has completed Good Clinical Practice (GCP) training on 7th July 2016 which included procedures on consent with vulnerable participants. Following the GCP training, the lead researcher will adhere to the NIHR guidelines on obtaining consent. The training provides information on policies and guidelines in the ethical and practical elements of gaining informed consent from vulnerable adults. GCP highlights the primary practical focus as the rights, safety and well-being of participants and the quality of the research data which is essential to the researchers and project. This includes steps that are taken for safeguarding of participants to ensure their rights, safety and well-being are protected.

Training has also covered informed consent with adults lacking capacity and an overview of the Mental Capacity Act. This research project does not intend to include individuals who lack capacity. The assessment of capacity will be through the lead researcher's communication with the participant, their informal caregiver and the aid from the organisation/route through which they were recruited. If there is any circumstance in which the lead researcher is unsure if the individual has capacity to provide voluntary, fully informed consent (e.g. due to cognitive impairment) the interview will not take place. Should it become apparent during interview that they don't have capacity, tactfully and politely end interview, thank them then discard their data.

A full DBS check has also been obtained by the lead researcher on 21:09:2016.

23 Please describe the procedures used to ensure children (i.e., persons under 18 years) are able to provide consent/assent to participation.

N/A

24 If appropriate, please state whether and how parental consent, or the consent of the legal guardian and/or order/declaration of the court, will be sought in relation to the participation of children in the research.

N/A

25 If the participant is unable to consent in their own right, will you seek the prior approval of an informed independent adult and any other person or body to the inclusion of the participant in the research?

	YES		**NO**	X	

State precisely what arrangements will be put in place.

Recruitment and Selection

The Research Ethics Committee will need to be satisfied with the effectiveness and propriety of recruitment and selection procedures given the participant involved, e.g., that the participant will not feel in any way obliged to take part, that advertisements do not appear to offer inducements. The Committee will be particularly interested in cases where a participant's relationship with the investigator could raise issues about the voluntary status or motive of the participant's involvement in the research (e.g., students).

26 How will the participants in the study be selected, approached and recruited (please indicate the inclusion and exclusion criteria)?

Participants will be purposively sampled based on their experience of dementia care. Service users will include individuals with dementia of no specified type and to varying degrees, but only where capacity still remains. Family members and informal caregivers of individuals with dementia will also be sought. They may or may not live with individual, and it may be that they have lost someone to dementia or have a relative who has been hospitalised or institutionalised. Seeking the broad experiences of service users will be invaluable in identifying how the model may plug a gap in community services for dementia. Where possible and appropriate, both parties of the caring dyad will be interviewed.

Professional stakeholders will include individuals who have worked in health and social care for the dementia population, or have had previous experience in interventions aiming to coordinate care for community-based populations.

Recruitment will take place through existing networks at UEMS, including PenCLAHRC's Dementia Care Research Programme (DCP) and the network of contacts for patient and public involvement in research (PPI). Once ethical approval has been granted, the Join Dementia Research database will be contacted regarding recruitment of service users. Personal contacts of the lead researcher and their supervisors will also be contacted to determine whether they may wish to participate in the study.

Recruitment process:

1. The lead researcher will send a letter to individuals and departments/organisations identified through the outlined resources.
2. Individuals showing interest in participating will be contacted by the lead researcher, either by telephone or in person, to discuss the study. They will be provided with the information sheet and will have opportunity to discuss and queries regarding the study and participation.
3. Following verbal agreement for participation, the individual will be sent the consent form and the model description to read through in preparation for the interview.
4. A convenient time and location will be arranged for the interview to take place.

If you are proposing to advertise, please include a copy of the advert to be used at the end of your application.

27 Where are you recruiting the participants?

The purposive sampling of participants will be done in a staggered approach through a number of channels. Primarily, the lead researcher will firstly use existing networks at UEMS, including PenCLAHRC's Dementia Care Research Programme (DCP) and the network of contacts for patient and public involvement in research (PPI), to contact potential stakeholders. If these existing channels do not provide enough recruitment, additional routes will be used including advertisement in the CLAHRC newsletter, the University campus and through relevant twitter accounts.

Personal contacts of the lead researcher and their supervisors will also be contacted to determine whether they may wish to participate in the study. These contacts will only be professional stakeholders working in health or social care settings.

Once ethical approval for the study has been given, the lead researcher will contact the Join Dementia Research (JDR) database to register interest in service user recruitment. The JDR database is a National Institute for Health Research (NIHR) initiative to encourage and register interest for participating in dementia research. For professionals, it can be used in research to identify potential participants, screen and contact volunteers, and run feasibility tests for future studies. The database recruits thousands of potential volunteers who want to be involved in research, who have a wide variety of backgrounds and experience.

28 Relationship of participant to investigator:					
29 Will the participants take part on a fully voluntary basis?					
	YES	X	**NO**		
30 Will students (e.g. PCMD, UEMS, other Schools or Colleges) be involved as participants in the research project?					
	YES		**NO**	X	
If yes, please provide full details.					
31 Will payments or other inducements be made to participants?					
	YES		**NO**	X	
If yes, give amounts, type and purpose.					
Information to Participants and Consent *If your study involves the collection and storage of human samples, please refer to the University Human Tissue Act Management Handbook and follow the guidelines for obtaining informed consent.*					
32 Will participants be informed of the purpose of the research?					
	YES	X	**NO**		
If no, please explain why.					
33 Will the participants be given a written information sheet?					
	YES	X	**NO**		
If yes, please use the sample at Appendix 2*					
If no, please explain why and delete Appendix 2.					
*Two information sheets have been drafted. One for service user stakeholder groups and one for health and social care professional stakeholders					
34 Will written consent be obtained?					

	YES	X	**NO**		
If yes, please use the sample at Appendix 3					
If no, please explain why and delete Appendix 3.					
35 Where potential participants will/may suffer from any difficulties of communication, state the methods to be employed both to present information to the participants and achieve consent. *If written, please include a copy at the end of your application.*					
In a section of the target population (individuals with dementia), it is possible that some participants will have communication difficulties such as hearing, sight or speech problems. We will try to include flexibility within the study to allow for the inclusion of all participants. For example, if necessary the participant will have the option to have a carer or family member present in the interview for support. The researcher will allow for extra time for interviews and give the option of splitting the interview across two sessions if needed. Participants will be encouraged to use communication aids where necessary (e.g. hearing aids, lightwriters), and the researcher will oblige in rephrasing, amplifying or writing down the questions where necessary.					
36 Ensure that the Information Sheet includes details of the participants' right to withdraw from the study at any time without penalty.					
Where relevant (should incidental significant findings emerge during the course of a study)					
36.1 Will any information be given to the participants' GP (if deemed necessary)?					
	YES		**NO**	X	
36.2 Have the participants consented to having their GP informed?					
	YES		**NO**	X	

37 Please state what measures will be taken to protect the confidentiality of the participant's data (i.e., arising out of the research and contained in personal data).
Confidentiality and anonymity will be guaranteed through a number of processes. All personal data including name and demographics of participants will remain confidential and held in accordance with the Data Protection Act 1998. Prior to the study commencing, each participant will be allocated a unique study identification number. All documents with personal details will be kept separately from documents matching the unique study identification number. Signed consent forms and contact details will also be stored separately from research materials including the recordings and transcripts of data. All of the research

data will be anonymised and only identifiable by the unique study number, and once accuracy checks of transcripts are complete, the recordings of interviews will be deleted.

The participants will be informed that in the unlikely case the researcher felt they may be a risk to themselves or others then a risk assessment will be conducted and a risk management protocol will be followed. The most appropriate action will be taken which may include contact or referral the GP or appropriate mental health services.

38 How will the data be stored during the life of the project?

All data will be anonymous from transcription onwards, with recordings of interviews being deleted after thorough accuracy checks against transcripts. All electronic data including interview transcripts will be kept on a password-protected computer at the University of Exeter, with access to the files being restricted to the research team only. The university regularly backs up electronic files on a secure, encrypted server. Transcribers, if not the named researchers, will be provided with anonymised interview files and no further information.

Hard copies of documents relating to the study and participants, such as consent forms, will be stored in a locked filing cabinet. These will be scanned and uploaded onto the secure server at the University of Exeter.

39 University of Exeter Guidelines state that primary data generated in the course of research must be kept securely in paper or electronic format, as appropriate and held normally for a period of five years (or as required by the funding body) after the completion of a research project.
http://www.exeter.ac.uk/research/toolkit/throughout/ethics/goodpractice/

Please provide details of how data will be stored, how long the data will be retained following completion of the study and how the data will be disposed of once this period has ended

In accordance to the University of Exeter recommendations, the data will be held and stored by the research team for 5 years after the completion of the study.

40 Who will be ultimately responsible for data storage and disposal for this project?

Amy Backhouse and supervisor, Chris Dickens, will have the responsibility of disposing of the data.

41 How will participants be informed of the results of the study if they so wish?

Upon completion of the study, a summary report of findings in the form of a leaflet will be available. This will be offered to all participants.

The participants will also be informed that the study will form part of a PhD thesis which will be available upon completion, and disseminated through publications, conference presentations and posters, and other educational resources.

42 Risk to research participants

42.1 do you think there are any ethical problems or special considerations/hazards with the proposed Study? If so, please describe

We do not anticipate any medical or legal problems arising as a result of the study. Should the participant feel any discomfort or raise any concerns during the course of the interview or the study, the researcher will address these immediately in the most appropriate manner. If the researcher becomes aware of any unusual behaviour during the interview that indicates the participant may be in distress, the interview will be stopped immediately.

In the unlikely event that the researcher feels that a risk assessment is required, an assessment will be conducted and a standard protocol for risk management will be followed. Where a risk is detected, the most appropriate action will take place; this may include contact and referral to the GP or to appropriate mental health services to ensure the safety of the participant.

Researchers contact information will be available from the start of the study, and participants will be able to contact them about any concerns they may have. The researcher will have responsibility in reminding all participants of the voluntary nature of the study and that they have the right to withdraw at any time without prejudice.

43 Does your proposed study require a Health and Safety risk assessment and if so, has this been carried out?

YES		NO	X	

44 Are there any potential conflicts of interest arising from the project, deriving from relationships with collaborators/sponsors/participants/interest groups?					
	YES		**NO**	X	
Please disclose all relevant personal and commercial interests.					

References:

1. Spotlight on Dementia Care. A Health Foundation improvement report: The Health Foundation; 2011.
2. Improving dementia services in England – an interim report. London; National Audit Office: 2010.
3. Braun V. & Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 2006; 3(2), 77-101.
4. Mason M. Sample size and saturation in PhD studies using qualitative interviews. *Forum: Qualitative Social Research*. 2010; 11(3): Art. 8. http://nbn-resolving.de/urn:nbn:de:0114-fqs100387.
5. Guest G, Bunce A, Johnson L. How many interviews are enough? an experiment with data saturation and variability. *Field Methods*. 2006; 18(1): 59–82.
6. Given M. *The Sage Encyclopaedia of Qualitative Research Methods (Vol. 2)*. Los Angeles, Sage; 2008.

Appendix 16: The COREQ 32 item checklist for interviews and focus groups

Topic	Item no.	Guide Questions/ Descriptions	Reported on Page no.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	164
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1, 164
Occupation	3	What was their occupation at the time of the study?	N/A
Gender	4	Was the researcher male or female?	N/A
Experience and training	5	What experience or training did the researcher have?	164
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	160, 161
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	161, 162
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	237
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	58, 165
Participant selection			

Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	160
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	164
Sample size	12	How many participants were in the study?	168
Non-participation	13	How many people refused to participate or dropped out? Reasons?	168
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	164
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	168
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	169, 170
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	161
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	164
Field notes	20	Were field notes made during and/or after the interview or focus group?	167
Duration	21	What was the duration of the inter views or focus group?	168, 169, 170
Data saturation	22	Was data saturation discussed?	160, 215
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	216
Domain 3: analysis and findings			

Data analysis			
Number of data coders	24	How many data coders coded the data?	165
Description of the coding tree	25	Did authors provide a description of the coding tree?	311
Derivation of themes	26	Were themes identified in advance or derived from the data?	165
Software	27	What software, if applicable, was used to manage the data?	165
Participant checking	28	Did participants provide feedback on the findings?	N/A
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	174-211
Data and findings consistent	30	Was there consistency between the data presented and the findings?	211
Clarity of major themes	31	Were major themes clearly presented in the findings?	172, 173
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	174-211

Appendix 17: An example of coding of interview data in the qualitative study

Theme	Subthemes	Categories	Codes	Example
Societal Attitudes	Ageism	Stigma	Embarrassment	*Oh and the first time I took him out, he says no I don't want to go outside, he didn't want to go out because he didn't want people to see him*
			Family/ friends don't understand	*That is the one thing, the problem you have with family because the family don't understand* *But people don't understand, even in the family, they just don't understand what's going on*
			Ignorance	*I mainly told you that for two reasons, you know one; what can happen through ignorance. I'm at fault partly because I didn't appreciate the fact that she didn't know how to handle Alzheimer's.*
			Need to raise public awareness	*… I don't watch it but the vicar has dementia and they say do you think it is on television enough and I said no …. But with dementia they need to advertise that people have got it.*
		Institutional discrimination	Better understanding of dementia and needs	*Because general nurses are not necessarily trained, especially the old ones, to be aware or to cope with people with dementia, their needs and certainly some of their behaviours. The system needs to change to address this, being task oriented is not helpful at all, you have to sing and dance.*
			Reflection of societal attitudes	*I think society carries within it, and all of us carry within us, a lot of prejudices about people with mental illness, about elderly people, about people with dementia … and to some extent that's projected within institutions*

Lack of understanding	Need to raise public awareness	*And considering how prevalent it is, there needs to be sort of public awareness campaigns about, sort of anyone who works in public services*
	Need to train public facing staff	*We had a terrible one with, it was NatWest … I can't remember exactly what she said but I said I'm sorry but I have dementia and she said well you shouldn't be banking if you've got dementia*
Generational differences	As you get older you worry about dementia	*Or perhaps you're just worrying about dementia and you don't need to worry, because loads of people say I walk into a room and I forget why I walked in. You do that when you're 20 and you think I'm being silly and you do it when you're 70 and you think I've got dementia.*
	Difficulty in changing attitudes	*But then a lot of people of that generation go oh I'm fine and carry on, so it's difficult to kind of, you can't change people's attitudes … I've learnt, I always thought that you could change everyone, what they think, but you can't change deep seated beliefs.*

REFERENCES

1. Cicero, M.T. (1988). Cato Maior de Senectute. *In:* Powell, J.G.F. (Ed.) *Cambridge Classic Texts and Commentaries*. Cambridge University Press.
2. A lbou, P. (2012). Esquirol and dementia. *Histoire des Sciences Medicales*, 46(1), 45-53.
3. Boller, F. & Forbes, M.M. (1998). History of dementia and dementia in history: an overview. *Journal of Neurological Sciences*, 158(2), 125-33.
4. World Health Organisation (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva, Switzerland: World Health Organisaiton.
5. American Psychiatric Association (1994). *Diagnostic and statistical manual of mental disorders 4th edition*. Washington, DC: American Psychiatric Association.
6. American Psychiatric Association (2012). *Diagnostic and statistical manual of mental disorders 5th edition*. Arlington, VA: American Psychiatric Association.
7. Prince, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., Wittenberg, R., Adelaja, B., Hu, B., King, D., Rehill, A., Salimkumar, D. (2014). *Dementia UK: Update*. London, UK: Alzheimer's Society.
8. Tomlinson, B.E., Blessed, G. & Roth, M. (1970). Observations on the brains of demented old people. *Journal of Neurological Sciences*, 11(3), 205-42.
9. Loehr, J.L. & Malone, M.L. (2013). *Here's How to Treat Dementia*. San Diego, United States: Plural Publishing Inc.
10. Castellani, R.J., Rolston, R.K. & Smith, M.A. (2010). Alzheimer Disease. *Disease-a-month*, 56(9), 484-546.
11. Alzheimer's Association (2009). Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 5(3).
12. Alzheimer's Association (2017). Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 13, 325-373.
13. Ahlskog, J.E. (2013). *Dementia with Lewy Bodies and Parkinson's Disease Patients: Patient, Family and Clinician Working Together for Better Outcomes*. New York, United States: Oxford University Press.
14. The Lund Manchester Groups (1994). Clinical and neuropathological criteria for frontotemporal dementia. The Lund and Manchester Groups. *Journal of Neurology, Neurosurgery, and Psychiatry*, 57(4), 416-418.
15. Zekry, D., Duyckaerts, C., Moulias, R., Belmin, J., Geoffre, C., Herrmann, F. & Hauw, JJ. (2002). Degenerative and vascular lesions of the brain have synergistic effects in dementia of the elderly. *Acta Neuropathologica*, 103(5), 481-7.
16. Prince, M., Guerchet, M., Ali, G.C., Wu, Y.T. & Prina, M. (2015). *World Alzheimer Report 2015; The Global Impact of Dementia, an Analysis of Prevalence, Incidence, Costs and Trends*. London, UK: Alzheimer's Disease International.
17. Savva , G.M., Wharton, S.B., Ince, P.G., Forster, G., Matthews, F.E. & Brayne, C. (2009). Age, Neuropathology, and Dementia. *New England Journal of Medicine*, 360(22), 2302-2309.
18. Snowden, M.B., Atkins, D.C., Steinman, L.E., Bell, J.F., Bryant, L.L., Copeland, C. & Fitzpatrick, A.L. (2015). Longitudinal Association of Dementia and Depression. *The American Journal of Geriatric Psychiatry*, 23(9), 897-905.
19. Rose, K.M., Fagin, C.M. & Lorenz, R. (2010). Sleep disturbances in dementia: What they are and what to do. *Journal of gerontological nursing*, 36(5), 9-14.
20. Bliwise, D.L. (2004). Sleep disorders in Alzheimer's disease and other dementias. *Clinical Cornerstone*, 6 Suppl 1A, S16-28.
21. Kunik, M.E., Snow, A.L., Davila J.A., Steele A.B., Balasubramanyam, V., Doody, R.S., Schulz, P.E., Kalavar, J.S. & Morgan, R.O. (2010). Causes of aggressive behavior in patients with dementia. *The Journal of Clinical Psychiatry*, 71(9), 1145-52.

22. Ballard, C. & Corbett, A. (2010). Management of neuropsychiatric symptoms in people with dementia. *CNS Drugs*, 24(9), 729-39.
23. Lai, C.K.Y. & Arthur, D.G. (2003). Wandering behaviour in people with dementia. Journal *of Advanced Nursing*, 44(2), 173-182.
24. Poblador-Plou, B., Calderon-Larranaga, A., Marta-Moreno, J., Hancco-Saavedra, J., Sicras-Mainar, A., Soljak, M. & Prados-Torres, A. (2014). Comorbidity of dementia: a cross-sectional study of primary care older patients. *BMC Psychiatry*, 14(1), 84.
25. Lopponen, M.K., Isoaho, R.E., Raiha, I.J., Vahlberg, T.J., Loikas, S.M., Takala, T.I., Puolijoki, H., Irjala, K.M. & Kivela, S.L. (2004). Undiagnosed diseases in patients with dementia--a potential target group for intervention. *Dementia and Geriatric Cognitive Disorders*, 18(3-4), 321-329.
26. Bauer, K., Schwarzkopf, L., Graessel, E. & Holle, R. (2014). A claims data-based comparison of comorbidity in individuals with and without dementia. *BMC Geriatrics*, 14(1), 10.
27. Melis, R.J., Marengoni, A., Rizzuto, D., Teerenstra, S., Kivipelto, M., Angleman, S.B. & Fratiglioni, L. (2013). The influence of multimorbidity on clinical progression of dementia in a population-based cohort. *PLoS One*, 8(12), e84014.
28. Sampson, E.L., Blanchard, M.R., Jones, L., Tookman, A. & King, M. (2009). Dementia in the acute hospital: prospective cohort study of prevalence and mortality. *British Journal of Psychiatry*, 195(1), 61-66.
29. Martin-Garcia, S., Rodriguez-Blazquet, C., Martinez-Lopez, I., Martinez-Martin, P. & Forjaz, M.J. (2013). Comorbidity, health status, and quality of life in institutionalized older people with and without dementia. *International Psychogeriatrics*, 25(7), 1077-1084.
30. Butcher, H.K., Holkup, P.A. & Buckwalter, K.C. (2001). The experience of caring for a family member with Alzheimer's disease. *Western Journal of Nursing Research,* 23(1), 33-55.
31. Schulz, R., et al., *Predictors of complicated grief among dementia caregivers: a prospective study of bereavement.* Am J Geriatr Psychiatry, 2006. **14**(8): p. 650-8.
32. Gaugler, J.E., Kane, R.L., Kane, R.A. & Newcomer, R. (2005). Unmet care needs and key outcomes in dementia. *The Journal of the American Geriatric Society*, 53(12), 2098-2105.
33. Kiecolt-Glaser, J.K., Dura, J.R., Speicher, C.E., Trask, O.J. & Glaser, R. (1991). Spousal caregivers of dementia victims: longitudinal changes in immunity and health. *Psychosomatic Medicine*, 53(4), 345-362.
34. Draper, B.M., Poulos, C.J., Cole, A.M., Poulos, R.G. & Ehrlich, F. (1992). A comparison of caregivers for elderly stroke and dementia victims. *The Journal of the American Geriatric Society*, 40(9), 896-901.
35. Grafstrom, M., Fratiglioni, L., Sandman, P.O. & Winblad, B. (1992). Health and social consequences for relatives of demented and non-demented elderly. A population-based study. *Journal of Clinical Epidemiology*, 45(8), 861-870.
36. World Health Organisation & Alzheimer's Disease International (2012). *Dementia: a public health priority*. Geneva, Switzerland: World Health Organisation.
37. Department of Health (2012). *Prime Minister's challenge on dementia: delivering major improvements in dementia care and research by 2015.* London, UK: Department of Health.
38. Department of Health (2015). *Prime Minister's Challenge on Dementia 2020.* London, UK: Department of Health.
39. Office of National Statistics (2016). *Population Estimates for UK, England and Wales, Scotland and Northern Ireland: mid-2016.* London, UK: Office for National Statistics.
40. Ferri, C.P., Prince, M., Brayne, C., Brodaty, H., Fratiglioni, L., Ganguli, M., Hall, K., Hasegawa, K., Hendrie, H., Huang, Y., Jorm, A., Mathers, C., Menezes, P.R., Rimmer, E., Scazufca, M. & Alzheimer's Disease International (2005). Global prevalence of dementia: a Delphi consensus study. *Lancet*, 366(9503): 2112-2117.

41. Prince, M., Bryce, R., Albanaese, E., Wimo, A., Ribeiro, W. & Ferri, C.P. (2013). The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimers and Dementia*, 9(1), 63-75.
42. Rizzi, L., Rosset, I. & Roriz-Cruz, M. (2014). Global epidemiology of dementia: Alzheimer's and vascular types. *Biomed Research International*, ID 908915.
43. Suzman, R., Willis, D.P & Manton, K.G. (1992). *The Oldest old*. New York, United States: Oxford University Press.
44. Panza, F., Solfrizzi, V., Colacicco, A.M., D'Introno, A., Capurso, C., Torres, F., Del Parigi, A., Capurso, S. & Capurso, A. (2004). Mediterranean diet and cognitive decline. *Public Health Nutrition*, 7(7), 959-963.
45. Hsu, T.M. & Kanoski, S.E. (2014). Blood-brain barrier disruption: mechanistic links between Western diet consumption and dementia. *Frontiers in Aging Neuroscience*, 6, 88.
46. Shakersain, B., Santoni, G., Larsson, S.C., Faxen-Irving, G., Fastbom, J., Fratiglioni, L. & Wu, W. (2016). Prudent diet may attenuate the adverse effects of Western diet on cognitive decline. *Alzheimers and Dementia*, 12(2), 100-109.
47. Martin, A., Cherubini, A., Andres-Lacueva, C., Paniagua, M. Joseph, J. (2002). Effects of fruits and vegetables on levels of vitamins E and C in the brain and their association with cognitive performance. *The Journal of Nutrition, Health and Aging*, 6(6), 392-404.
48. Luchsinger, J.A., Noble, J.M. & Scarmeas, N. (2007). Diet and Alzheimer's disease. *Current Neurology and Neuroscience Reports*, 7(5), 366-72.
49. Yusuf, S., Reddy, S., Ounpuu, S. & Anand, S. (2001). Global burden of cardiovascular diseases: part I: general considerations, the epidemiologic transition, risk factors, and impact of urbanization. *Circulation*, 104(22), 2746-2753.
50. Pi-Sunyer, F.X. (2002). The obesity epidemic: pathophysiology and consequences of obesity. *Obesity Research*, 10 Suppl 2, 97s-104s.
51. Letenneur, L., Gilleron, V., Commenges, D., Helmer, C., Orgogozo, J.M. & Dartiques, J.F. (1999). Are sex and educational level independent predictors of dementia and Alzheimer's disease? Incidence data from the PAQUID project. *Journal of Neurology, Neurosurgery & Psychiatry*, 66(2), 177-183.
52. Stern, Y. (2012). Cognitive reserve in ageing and Alzheimer's disease. *Lancet neurology*, 11(11), 1006-1012.
53. Wu, Y.T., Beiser, A.S., Breteler, M.M.B., Fratiglioni, L., Helmer, C., Hendrie, H.C., Honda, H., Ikram, M.A., Langa, K.M., Lobo, A., Matthews, F.E., Ohara, T., Peres, K., Qiu, C., Seshadri, S., Sjolund, B.M., Skoog, I. & Brayne, C. (2017). The changing prevalence and incidence of dementia over time — current evidence. *Nature Reviews Neurology*, 13(6), 327-339.
54. Prince, M. & Jackson, J. (2009). *World Alzheimer Report 2009*. London, UK: Alzheimer's Disease International.
55. Nolte, H. & McKee, M. (2008). *Caring for people with chronic conditions: a health systems perspective*. New York, USA: World Health Organisation.
56. Constandse, C.R., Ewart, S., Grisetti, M., McCarey, P., Pattison, A., Prentice, T., Sadki, R. & Vita-Finzi, L. (2005). *Preventing chronic disease: a vital investment.* Geneva, Switzerland: World Health Organisation.
57. Llewellyn, D. & Bayer, A. (2016). *Factsheet: Risk factors for dementia*. London, UK: Alzheimer's Society.
58. Department of Economic and Social Affairs Population Division (2015). *World Population Ageing.* New York, USA: United Nations.
59. Ebly, E.M., Hogan, D.B. & Rockwood, K. (1999). Living alone with dementia. *Dementia and Geriatric Cognitive Disorders*, 10(6), 541-548.
60. Sibley, A., MacKnight, C., Rockwood, K., Fisk, J., Gauthier, S., Guzman, D.A., Hogan, D.B. & Consortium to Investigate Vascular Impairment of Cognition (2002). The effect of the living

situation on the severity of dementia at diagnosis. *Dementia and Geriatric Cognitive Disorders*, 13(1), 40-45.
61. Brodaty, H. & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, 11(2), 217-228.
62. Bourn, J., Ahmad, S., Taylor, K., O'Neill, M., New, B., Rapkin, C., Kyte, F., Wijeratne, R. & Robinson, E. (2007). *Improving services and support for people with dementia*. London, UK: National Audit Office.
63. Anderson, D., Baldwin, B., Barker, A., Forsyth, D., Guthrie, E., Holmes, J., Ratcliffe, J. & Richman, A. (2005). *Who cares wins: improving the outcomes for older people admitted to the general hospital: Guidelines for the development of liaison mental health services for older people*. London, UK: Royal College of Psychiatrists.
64. Alzheimer's Society (2009). *Counting the costs: caring for people with dementia on hospital wards.* London, UK: Alzheimer's Society.
65. Lakey, L., Quince, C., Kane, M. & Saunders, T. (2012). *Dementia 2012: A national challenge.* London, UK: Alzheimer's Society.
66. Edwards, N. (2014). *Community services: how they can transform care.* London, UK: The King's Fund.
67. NHS England (2013). *Everyone counts: Planning for patients 2014/15 - 2018/19*. London, UK: NHS England.
68. Peel, E. & Harding, R. (2014). 'It's a huge maze, the system, it's a terrible maze': dementia carers' constructions of navigating health and social care services. *Dementia*, 13(5), 642-661.
69. Kane, M. (2015). *Dementia 2015: aiming higher to transform lives*. London, UK: Alzheimer's Society.
70. Robertshaw, D. & Cross, A. (2017). Experiences of Integrated Care for dementia from family and carer perspectives: A framework analysis of massive open online course discussion board posts. *Dementia*, 0(0), 1471301217719991.
71. Skipper, M. (2010). Managed clinical networks*. British Dental Journal*, 209, 241-242.
72. Halliday, K., Maslin, S. & Queenborough, R. (2009). *Integrated care pilot programme.* London, UK: Department of Health.
73. NHS England (2015). *Integrated care pioneers* [Accessed 2016 December]; Available from: https://www.england.nhs.uk/integrated-care-pioneers/.
74. Fairbairn, A., Gould, N., Kendall, T., Ashley, P., Bainbridge, I., Bower, L., Brown, S., Duncan, A., Garner, G., Gilliard, J., Harrison, K., Hopkins, S., Iliffe, S., Jones, R., Manthorpe, J., Mavranezouli, I., Meader, N., Murrell, M., O'Brien, J., Pettinari, C., Stockton, S., Taylor, C., Weithaler, S., Whittington, C., Wood, J., Woods, B., Young, C. & Hughes, J. (2006). *Dementia: supporting people with dementia and their carers in health and social care.* London, UK: NICE.
75. Samsi, K. & Manthorpe, J. (2014). Care pathways for dementia: current perspectives. *Clinical Interventions in Aging*, 9, 2055-2063.
76. World Health Organisation (2008). *Integrated Health Services.* Geneva, Switzerland: World Health Organisaiton.
77. Cahill, S., O'Shea, E., & Pierce, M. (2012). *Creating Excellence in Dementia Care*. DSIDC's Living with Dementia Research Programme, School of Social Work and Social Policy, Trinity College Dublin, Irish Centre for Social Gerontology & National University of Ireland, Galway.
78. Wagner, E.H., Austin, B.T. & Von Korff, M. (1996). Organizing care for patients with chronic illness. *The Milbank Quarterly*, 74(4), 511-44.
79. Renders, C.M., Valk, G.D., Griffin, S.J., Wagner, E.H., Eijk Van, J.T. & Assendelft, W.J. (2001). Interventions to improve the management of diabetes in primary care, outpatient, and community settings. *Diabetes care*, 24(10), 1821-1833.
80. Bodenheimer, T., Wagner, E.H. & Grumbach, K. (2002). Improving primary care for patients with chronic illness: The chronic care model, part 2. JAMA, 288(15), 1909-1914.

81. Katon, W., Rutter, C., Ludman, E.J., Von Korff, M., Lin, E., Simon, G., Bush, T., Walker, E. & Unutzer, J. (2001). A randomized trial of relapse prevention of depression in primary care. *Archives of General Psychiatry*, 58(3), 241-247.
82. Jaglal, S.B., Guilcher, S. J. T., Bereket, T., Kwan, M., Munce, S., Conklin, J., Versnel, J., Packer, T., Verrier, M., Marras, C., Pitzul, K. B. & Riopelle, R. (2014). Development of a Chronic Care Model for Neurological Conditions (CCM-NC). *BMC Health Services Research*, 14:409.
83. Wagner, E.H., Glasgow, R.E., Davis, C., Bonomi, A.E., Provost, L., McCulloch, D., Carver, P. & Sixta, C. (2001). Quality improvement in chronic illness care: a collaborative approach. *The Joint Commission Journal on Quality Improvement*, 27(2), 63-80.
84. Iliffe, S., Waugh, A., Poole, M., Bamford, C., Brittain, K., Chew-Graham, C., Fox, C., Katona, C., Livingston, G., Manthorpe, J., Steen, N., Stephens, B., Hogan, V. & Robinson, L. (2014). The effectiveness of collaborative care for people with memory problems in primary care: results of the CAREDEM case management modelling and feasibility study. *Health Technology Assessment*, 18(52), 1-148.
85. Eloniemi-Sulkava, U., Notkola, I.L., Hentinen, M., Kivela, S.L., Sivenius, J. & Sulkava, R. (2001). Effects of supporting community-living demented patients and their caregivers: a randomized trial. *The Journal of the American Geriatric Society*, 49(10), 1282-1287.
86. Bass, D.M., Clark, P.A., Looman, W.J., McCarthy, C.A. & Eckert, S. (2003). The Cleveland Alzheimer's managed care demonstration: outcomes after 12 months of implementation. *Gerontologist*, 43(1), 73-85.
87. Dias, A., Dewey, M.E., D'Souza, J., Dhume, R., Motghare, D.D., Shaji, K.S., Menon, R., Prince, M. & Patel, V. (2008). The effectiveness of a home care program for supporting caregivers of persons with dementia in developing countries: a randomised controlled trial from Goa, India. *PLoS One*, 3(6), e2333.
88. Gladman, J.R., Jones, R.G., Radford, K., Walker, E. & Rothera, I. (2007). Person-centred dementia services are feasible, but can they be sustained? *Age & Ageing*, 36(2), 171-176.
89. Kadu, M.K. & Stolee, P. (2015). Facilitators and barriers of implementing the chronic care model in primary care: a systematic review. *BMC Family Practice*, 16:12.
90. Von Korff, M., Gruman, J., Schaefer, J., Curry, S.J. & Wagner, E.H. (1997). Collaborative management of chronic illness. *Annals of Internal Medicine*, 127(12), 1097-1102.
91. Gunn, J., Diggens, J., Hegarty, K. & Blashki, G. (2006). A systematic review of complex system interventions designed to increase recovery from depression in primary care. *BMC Health Services Research*, 6(1), 88.
92. Katon, W., Von Korff, M., Lin, E., Simon, G., Walker, E., Unutzer, J., Bush, T., Russo, J. & Ludman, E. (1999). Stepped collaborative care for primary care patients with persistent symptoms of depression: A randomized trial. *Archives of General Psychiatry*, 56(12), 1109-1115.
93. Katon, W.J., Roy-Byrne, P., Russo, J. & Cowley, D. (2002). Cost-effectiveness and cost offset of a collaborative care intervention for primary care patients with panic disorder. *Archives of General Psychiatry*, 59(12), 1098-1104.
94. Katon, W.J., Von Korff, M., Lin, E.H., Simon, G., Ludman, E., Russo, J., Ciechanowski, P., Walker, E. & Bush, T. (2004). The pathways study: A randomized trial of collaborative care in patients with diabetesand depression. *Archives of General Psychiatry*, 61(10), 1042-1049.
95. Richards, D.A., Hill, J.J., Gask, L., Lovell, K., Chew-Graham, C., Bower, P., Cape, J., Pilling, S., Araya, R., Kessler, D., Bland, M., Green, C., Gilbody, S., Lewis, G., Manning, C., Hughes-Morley, A. & Barkham, M. (2013). Clinical effectiveness of collaborative care for depression in UK primary care (CADET): cluster randomised controlled trial. *British Medical Journal*, 347, doi: https://doi.org/10.1136/bmj.f4913.
96. Zatzick, D., Roy-Byrne, P., Russo, J., Rivara, F., Droesch, R., Wagner, A., Dunn, C., Jurkovich, G., Uehara, E. & Katon, W. (2004). A randomized effectiveness trial of stepped collaborative care foracutely injured trauma survivors. *Archives of General Psychiatry*, 61(5), 498-506.

97. Gilbody, S., Bower, P., Fletcher, J., Richards, D. & Sutton, A.J. (2006). Collaborative care for depression: a cumulative meta-analysis and review of longer-term outcomes. *Archives of Internal Medicine*, 166(21), 2314-21.
98. Thota, A.B., Sipe, T.A., Byard, G.J., Zometa, C.S., Hahn, R.A., McKnight-Eily, L.R., Chapman, D.P., Abraido-Lanza, A.F., Pearson, J.L., Anderson, C.W., Gelenberg, A.J., Hennessy, K.D., Duff, F.F., Vernon-Smiley, M.E., Nease, D.E. Jr., Williams, S.P. & Community Preventive Services Task Force (2012). Collaborative care to improve the management of depressive disorders: a community guide systematic review and meta-analysis. *American Journal of Preventive Medicine*, 42(5), 525-38.
99. Holloway, F., McLean, E.K. & Robertson, J.A. (1991). Case management. *British Journal of Psychiatry*, 159, 142-148.
100. Rothman, J. (1992). *Guidelines for Case Management: Putting Research to Professional Use*. Michigan, USA: F.E. Peacock Publishers.
101. Case Management Society of America (2010). *Standards of Practice for Case Management.* Little Rock, Arkansas: Case Management Society of America.
102. Hutt, R., Rosen, R. & Janet, M. (2004). *Case-managing long-term conditions: what impact does it have in treatment of older people?* London, UK: The King's Fund.
103. NHS Modernisation Agency and Skills for Health (2005). *Case Management Competences Framework.* Bristol, UK: Department of Health.
104. Aubert, R.E., Herman, W.H., Waters, J., Moore, W., Sutton, D., Peterson, B.L., Bailey, C.M. & Koplan, J.P. (1998). Nurse case management to improve glycemic control in diabetic patients in a health maintenance organization. A randomized, controlled trial. *Annals of Internal Medicine*, 129(8), 605-612.
105. Hui, E., Lum, C.M., Woo, J., Or, K.H. & Kay, R. (1995). Outcomes of elderly stroke patients. *Stroke*, 26(9), 1616-1619.
106. Ethridge, P. & Lamb, G.S. (1989). Professional nursing case management improves quality, access and costs. *Nursing Management*, 20(3), 30-35.
107. Hudon, C., Chouinard, M.C., Lambert, M., Dufour, I. & Krieg, C. (2016). Effectiveness of case management interventions for frequent users of healthcare services: a scoping review. *BMJ Open*, 6(9).
108. Riegel, B., Carlson, B., Kopp, Z., LePetri, B., Glaser, D. & Unger, A. (2002). Effect of a standardized nurse case-management telephone intervention on resource use in patients with chronic heart failure. *Archives of Internal Medicine*, 162(6), 705-712.
109. van Steenbergen-Weijenburg, K.M., van der Feltz-Cornelis, C.M., Horn, E.K., van Marwijk, H.W.J., Beekman, A.T.F., Rutten, F.H. & Hakkaart-van Roijen, L. (2010). Cost-effectiveness of collaborative care for the treatment of major depressive disorder in primary care. A systematic review. *BMC Health Services Research*, 10(1), 19.
110. Grochtdreis, T., Brettschneider, C., Wegener, A., Watzke, B., Riedel-Heller, S., Harter, M. & Konig, H.H. (2015). Cost-Effectiveness of Collaborative Care for the Treatment of Depressive Disorders in Primary Care: A Systematic Review. *PLoS ONE*. 10(5): e0123078.
111. Reilly, S., Miranda-Castillo, C., Malouf, R., Hoe, J., Toot, S., Challis, D. & Orrell, M. (2015). Case management approaches to home support for people with dementia. *Cochrane Database of Systematic Reviews*, 1, Cd008345.
112. Pimouguet, C., Lavaud, T., Dartigues, J.F. & Helmer, C. (2010). Dementia case management effectiveness on health care costs and resource utilization: a systematic review of randomized controlled trials. Journal of Nutritional Health Aging, 14(8), 669-676.
113. Somme, D., Trouve, H., Drame, M., Gagnon, D., Couturier, Y. & Saint-Jean, O. (2012). Analysis of case management programs for patients with dementia: a systematic review. *Alzheimers & Dementia*, 8(5), 426-436.

114. Tam-Tham, H., Cepoui-Martin, M., Ronksley, P.E., Maxwell, C.J. & Hemmelgarn, B.R. (2013). Dementia case management and risk of long-term care placement: a systematic review and meta-analysis. *International Journal of Geriatric Psychiatry*, 28(9), 889-902.
115. Khanassov, V., Vedel, I. & Pluye, P. (2014). Case management for dementia in primary health care: a systematic mixed studies review based on the diffusion of innovation model. *Clinical Interventions in Aging*, 9, 915-928.
116. Khanassov, V., Vedel, I. & Pluye, P. (2014). Barriers to implementation of case management for patients with dementia: a systematic mixed studies review. *Annals of Family Medicine*, 12(5), 456-465.
117. Rogers, E.M. (2010). *Diffusion of Innovations, 4th Edition*. New York, USA: The Free Press.
118. Ross, S., Curry, N. & Goodwin, N. (2011). *Case management: what it is and how it can be implemented*. London, UK: The King's Fund.
119. Sargent, P., Pickard, S., Sheaff, R. & Boaden, R. (2007). Patient and carer perceptions of case management for long-term conditions. *Health & Social Care in the Community*, 15(6), 511-519.
120. Hughes, S.L., Weaver, F.M., Giobbie-Hurder, A., Manheim, L., Henderson, W., Kubal, J.D., Ulasevich, A. & Cummings, J. (2000). Effectiveness of team-managed home-based primary care: a randomized multicenter trial. *JAMA*, 284(22), 2877-85.
121. Dorr, D.A., Wilcox, A., Donnelly, S.M., Burns, L. & Clayton, P.D. (2005). Impact of Generalist Care Managers on Patients with Diabetes. *BMC Health Services Research*, 40, 1400-1421.
122. Challis, D., Hughes, J., Berzins, K., Reilly, S., Abell, J. & Stewart, K. (2010). *Self-care and case management in long-term conditions: the effective management of critical interfaces.* Southampton, UK: National Institute for Health Research Service Delivery and Organisation Programme.
123. Schraeder, C., Fraser, C.W., Clark, I., Long, B., Shelton, P., Waldschmidt, V., Kucera, C.L. & Lanker, W.K. (2008). Evaluation of a primary care nurse case management intervention for chronically ill community dwelling older people. *Journal of Clinical Nursing*, 17(11c), 407-417.
124. Jansen, A.P., van Hout, H.P., Nijpels, G., Rijmen, F., Droes, R.M., Pot, A.M., Schellevis, F.G., Stalman, W.A. & van Marwijk, H.W. (2011). Effectiveness of case management among older adults with early symptoms of dementia and their primary informal caregivers: a randomized clinical trial. *International Journal of Nursing Studies*, 48(8), 933-943.
125. Newcomer, R., Miller, R., Clay, T. & Fox, P. (1999). Effects of the Medicare Alzheimer's disease demonstration on Medicare expenditures. *Health Care Finance Reviews*, 20(4), 45-65.
126. Lam, L.C., Lee, J.S., Chung, J.C., Lau, A., Woo, J. & Kwok, T.C. (2010). A randomized controlled trial to examine the effectiveness of case management model for community dwelling older persons with mild dementia in Hong Kong. *International Journal of Geriatric Psychiatry*, 25(4), 395-402.
127. Bass, D.M., Judge, K.S., Snow, A.L., Wilson, N.L., Morgan, R.O., Maslow, K., Randazzo, R., Moye, J.A., Odenheimer, G.L., Archambault, E., Elbein, R., Pirraglia, P., Teasdale, T.A., McCarthy, C.A., Looman, W.J. & Kunik, M.E. (2014). A controlled trial of Partners in Dementia Care: veteran outcomes after six and twelve months. *Alzheimers Research & Therapy*, 6(1), 9.
128. Fortinsky, R.H., Unson, C.G.& Garcia, R.I. (2002). Helping Family Caregivers by Linking Primary Care Physicians with Community-Based Dementia Care Services:The Alzheimer's Service Coordination Program. *Dementia*, 1(2), 227-240.
129. Dang, S., Remon, N., Harris, J., Malphurs, J., Sandals, L., Cabrera, A.L. & Nedd, N. (2008). Care coordination assisted by technology for multiethnic caregivers of persons with dementia: a pilot clinical demonstration project on caregiver burden and depression. *Journal of Telemedicine & Telecare*, 14(8), 443-447.

130. Chiatti, C., Masera, F., Rimland, J.M., Cherubini, A., Scarpino, O., Spazzafumo, L. & Lattanzio, F. (2013). The UP-TECH project, an intervention to support caregivers of Alzheimer's disease patients in Italy: study protocol for a randomized controlled trial. *Trials*, 14(1), 155.
131. Callahan, C.M., Boustani, M.A., Unverzagt, F.W., Austrom, M.G., Damush, T.M., Perkins, A.J., Fultz, B.A., Hui, S.L., Counsell, S.R. & Hendrie, H.C. (2006). Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial. *JAMA*, 295(18), 2148-2157.
132. Eloniemi-Sulkava, U., Saarenheimo, M., Laakkonen, M.L., Pietila, M., Savikko, N., Kautianinen, H., Tilvis, R.S. Pitkala, K.H. (2009). Family care as collaboration: effectiveness of a multicomponent support program for elderly couples with dementia. Randomized controlled intervention study. *Journal of the American Geriatric Society*, 57(12), 2200-2208.
133. Tan, Z.S., Jennings, L. & Reuben, D. (2014). Coordinated care management for dementia in a large academic health system. *Health Affairs*, 33(4), 619-625.
134. Chu, P., Edwards, J., Levin, R. & Thomson, J. (2000). The use of clinical case management for early stage Alzheimer' patients and their families. *American Journal of Alzheimer's Disease*, 15(5), 284-290.
135. Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I & Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *The BMJ*, 337, a1655.
136. Bryman, A. (2016). *Social Research Methods 5th edition*. Oxford, UK: Oxford University Press.
137. Tranfield, D., Denyer, D. & Smart, P. (2003). Towards a Methodology for Developing Evidence-Informed Management Knowledge by Means of Systematic Review. *British Journal of Management*, 14(3), 207-222.
138. Backhouse, A., Dickens, C., McCabe, R. & Richards, D. (2015). Key components in models of community-based interventions coordinating care in dementia: a mixed studies systematic review protocol. *Systematic Reviews*, 4(1), 156.
139. Hannes, I. (2015). Building a case for mixed-methods reviews. *In:* Richards, D.A. & Hallberg, J.R. *Complex Interventions in Health: An Overview of Research Methods.* Oxton, UK: Routledge.
140. Nobit, G.W. & Hare, R.D. (1988). *Meta-ethnography: synthesising qualitative studies*. Newbury Park, USA: SAGE.
141. Sandelowski, M. & Barroso, J. (2007). *Handbook for Synthesizing Qualitative Research*. New York, USA: Springer Publishing Company.
142. Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., Hsu, R., Katbamna, S., Olsen, R., Smith, L., Riley, R. & Sutton, A.J. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology*, 6, 35.
143. Paterson, B.L. & Canam, C. (2001). *Meta-Study of Qualitative Health Research: A Practical Guide to Meta-Analysis and Meta-Synthesis*. Thousand Oaks, California: SAGE Publications.
144. Thomas, J. & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1), 45.
145. Haidich, A.B. (2010). Meta-analysis in medical research. *Hippokratia*, 14(Suppl 1), 29-37.
146. Song, F., Sheldon, T.A., Sutton, A.J., Abrams, K.R. & Jones, D.R. (2001). Methods for exploring heterogeneity in meta-analysis. *Evaluation & Health Professions*, 24(2), 126-151.
147. Richards, D.A. & Hallberg, I. (2015). *Complex Interventions in Health: An Overview of Research Methods*. Oxton, UK: Routledge.
148. Bleijenberg, N., de Man-Van Ginkel, J., Trappenberg, J.C., Ettema, R.G., Sino, C.G, Heim, N., Hafsteinsdottir, T.B., Richards, D.A. & Schuurmans, M.J. (2017). Increasing value and reducing research waste by optimising the development of complex interventions. *International Journal of Nursing Studies.* Manuscript no. IJNS-D-17-00853R1

149. Hoffmann, T.C., Glasziou, P.P., Boutron, I., Milne, R., Perera, R., Moher, D., Altman, D.G., Barbour, V., Macdonald, H., Johnston, M., Lamb, S.E., Dixon-Woods, M., McCulloch, P., Wyatt, J.C., Chan, A.W. & Michie, S. (2014). Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. *British Medical Journal*, 348, g1687.
150. Centre for Community Health and Development. Developing aLogic Model or Theory of change. University of Kansas. [Accessed 06/2015]; Available from: http://ctb.ku.edu/en/table-of-contents/overview/models-for-community-health-and-development/logic-model-development/main.
151. Butcher, H.K., Holkup, P.A., Park, M. & Maas, M. (2001). Thematic analysis of the experience of making a decision to place a family member with Alzheimer's disease in a special care unit. *Research in Nursing & Health*, 24(6), 470-480.
152. Sun, F. (2014). Caregiving stress and coping: A thematic analysis of Chinese family caregivers of persons with dementia. *Dementia*, 13(6), 803-818.
153. Borbasi, S., Jones, J., Lockwood, C. & Emden, C. (2006). Health Professionals' Perspectives of Providing Care to People with Dementia in the Acute Setting: Toward Better Practice. *Geriatric Nursing*, 27(5), 300-308.
154. Robinson, L., Dickinson, C., Bamford, C., Clark, A., Hughes, J. & Exley, C. (2013). A qualitative study: Professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but …'. *Palliative Medicine*, 27(5), 401-408.
155. Vaismoradi, M., Turunen, H. & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences*, 15(3), 398-405.
156. Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
157. Frith, H. & Gleeson, K. (2004). Clothing and Embodiment: Men Managing Body Image and Appearance. *Psychology of Men & Masculinity*, 5(1), 40-48.
158. Hayes, N. (1997). Theory-led thematic analysis: Social identification in small companies. *In:* Hayes, N. *Doing qualitative analysis in Psychology*. Hove, UK: Taylor & Francis.
159. Campbell, M., Fitzpatrick, R., Haines, A., Kinmonth, A.L., Sandercock, P., Spiegelhalter, D. & Tyrer, P. (2000). Framework for design and evaluation of complex interventions to improve health. *Britich Medical Journal*, 321(7262), 694-696.
160. Claridge, J.A. & Fabian, T.C. (2005). History and development of evidence-based medicine. *World Journal of Surgery*, 29(5), 547-53.
161. Cochrane, A. (1972). *Effectiveness and efficacy: random reflections on health services.* London, UK: Nuffield Provincial Hospital Trust.
162. Sackett, D.L. (1997). Evidence-based medicine. *Semin Perinatol*, 21(1), 3-5.
163. Peto, R., Collins, R. & Gray, R. (1995). Large-scale randomized evidence: large, simple trials and overviews of trials. *Journal of Clinical Epidemiology*, 48(1), 23-40.
164. Masic, I., Miokovic, M. & Muhamedagic, B. (2008). Evidence Based Medicine – New Approaches and Challenges. *Acta Informatica Medica*, 16(4), 219-225.
165. van der Weijden, T., Legare, F., Boivin, A., Burgers, J.S., van Veenendaal, H., Stiggelbout, A.M., Faber, M. & Elwyn, G. (2010). How to integrate individual patient values and preferences in clinical practice guidelines? A research protocol. *Implementation Science,* 5, 10.
166. Morgan, D.L. (2007). Paradigms Lost and Pragmatism Regained. *Journal of Mixed Methods Research*, 1(1), 48-76.
167. Doane, G.H. & Varcoe, C. (2005). *Family nursing as relational inquiry: developing health promoting practice.* Philadelphia, USA: Lippincott Williams & Wilkins.

168. Backhouse, A., Richards, D.A., McCabe, R., Watkins, R. & Dickens, C. (2017). Stakeholders perspectives on the key components of community-based interventions coordinating care in dementia: a qualitative systematic review. *BMC Health Services Research.* 17, 767.
169. Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., Shekelle, P. & Stewart, L.A. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews*, 4(1), 1.
170. Critical Appraisal Skills Programme. *CASP Qualitative Checklist.* [Accessed 04/2015]. Available from: http://www.casp-uk.net/casp-tools-checklists
171. Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B., Bonas, S., Booth, A. & Jones, D. (2007). Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. *Journal of Health Servives Research & Policy*, 12(1), 42-7.
172. Padgett, D. (1998). *Qualitative Methods in Social Work Research: Challenges and Rewards*. Thousand Oaks, California: SAGE Publications.
173. Bamford, C., Poole, M., Brittain, K., Chew-Graham, C., Fox, C., Iliffe, S., Manthorpe, J. & Robinson, L. (2014). Understanding the challenges to implementing case management for people with dementia in primary care in England: a qualitative study using Normalization Process Theory. *BMC Health Services Research*, 14(1), 549.
174. Iliffe, S., Robinson, L., Bamford, C., Waugh, A., Fox, C., Livingston, G., Manthorpe, J., Brown, P., Stephens, B., Brittain, K., Chew-Graham, C. & Katona, C. (2014). Introducing case management for people with dementia in primary care: a mixed-methods study. *British Journal of General Practice*, 64(628), e735-41.
175. Kosteniuk, J., Morgan, D., Innes, A., Keady, J., Stewart, N., D'Arcy, C. & Kirk, A. (2014). Who steers the ship? Rural family physicians' views on collaborative care models for patients with dementia. *Primary Health Care Research & Development*, 15(1), 104-10.
176. Minkman, M.M., Ligthart, S.A. & Huijsman, R. (2009). Integrated dementia care in The Netherlands: a multiple case study of case management programmes. *Health & Social Care Community*, 17(5), 485-94.
177. Van Mierlo, L.D., Meiland, F.J.M., van Hout, H.P.J. & Droes, R.M. (2014). Towards personalized integrated dementia care: a qualitative study into the implementation of different models of case management. *BMC Geriatrics*, 14(1), 84.
178. Yeo, A., Legard, R., Keegan, J., Ward, K., Nicholls, C.M. & Lewis, J. (2014). In-Depth Interviews. *In:* Ritchie, J., Lewis, J., Nicholls, C.M. & Ormston, R. *Qualitative Research in Practice: A guide for social science students and researchers*. London, UK: SAGE Publications.
179. de Lange, J., Deusing, E., van Asch, I. F., Peeters, J., Zwaanswijk, M., Pot, A. M. & Francke, A. L. (2018). Factors facilitating dementia case management: Results of online focus groups. *Dementia*, 17(1), 110-125.
180. Hirakawa, Y., Chiang, C. & Aoyama, A. (2017). A qualitative study on barriers to achieving high-quality, community-based integrated dementia care. *Journal of Rural Medicine*, 12(1), 28-32.
181. Jurgens, F.J., Clissett, P., Gladman, J.R. & Harwood, R.H. (2012). Why are family carers of people with dementia dissatisfied with general hospital care? A qualitative study. *BMC Geriatrics*, 12, 57.
181. Böhm, K., Schmid, A., Gotze, R., Landwehr, C. & Rothgang, H. (2013). Five types of OECD healthcare systems: Empirical results of a deductive classification. *Health Policy*, 113(3), 258-269.
183. McKeown, J., Clarke, A., Ingleton, C. & Repper, J. (2010). Actively involving people with dementia in qualitative research.*Journal of clinical nursing,* 19(13-14), 1935-1943.
184. Dewing, J. (2002). From Ritual to Relationship:A person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia*, 1(2), 157-171.

185. Kitson, A., Harvey, G. & McCormack, B. (1998). Enabling the implementation of evidence based practice: a conceptual framework. *Quality in Health Care*, 7(3), 149-58.
186. Murray, E., Treweek, S., Pope, C., MacFarlane, A., Ballini, L., Dowrick, C., Finch, T., Kennedy, A., Mair, F., O'Donnell, C., Ong, B.N., Rapley, T., Rogers, A. & May, C. (2010). Normalisation process theory: a framework for developing, evaluating and implementing complex interventions. *BMC Medicine*, 8, 63.
187. Backhouse, A., Ukoumunne, O.C., Richards, D.A., McCabe, R., Watkins, R. & Dickens, D. (2017). The effectiveness of community-based coordinating interventions in dementia care: a meta-analysis and subgroup analysis of intervention components. *BMC Health Services Research*, 17(1), 717.
188. Critical Appraisal Tool Programme. *CASP Randomised Controlled Trial Checklist*. [Accessed 06/2015]. Available from: http://www.casp-uk.net/casp-tools-checklists
189. Deeks, J.J., Higgins, J.P.T. & Altman, D.G. (2011). Chapter 9: Analysing data and undertaking meta-analyses. *In:* Higgins, J.P.T. & Green, S. *Cochrane Handbook for Systematic Reviews of Interventions*. Chichester, UK: John Wiley & Sons.
190. Samus, Q.M., Johnston, D., Black, B.S., Hess, E., Lyman, C., Vavilikolanu, A., Pollutra, J., Leoutsakos, J.M., Gitlin, L.N., Rabins, P.V. & Lyketsos, C.G. (2014). A multidimensional home-based care coordination intervention for elders with memory disorders: the maximizing independence at home (MIND) pilot randomized trial. *American Journal of Geriatric Psychiatry*, 22(4), 398-414.
191. Vickrey, B.G., Mittman, B.S., Connor, K.I., Pearson, M.L., Della Penna, R.D., Ganiats, T.G., Demonte, R.W.Jr., Chodosh, J., Cui, X., Duan, N. & Lee, M. (2006). The effect of a disease management intervention on quality and outcomes of dementia care: a randomized, controlled trial. *Annals of International Medicine*, 145(10), 713-726.
192. Chien, W.T. & Lee, I.Y. (2011). Randomized controlled trial of a dementia care programme for families of home-resided older people with dementia. *Journal of Advanced Nursing*, 67(4), 774-787.
193. Chien, W.T. & Lee, Y.M. (2008). A disease management program for families of persons in Hong Kong with dementia. *Psychiatric Services*, 59(4), 433-436.
194. Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences.* New York, NYC: Routledge Academic.
195. Bower, P., Gilbody, S., Richards, D.A., Fletcher, J. & Sutton, A. (2006). Collaborative care for depression in primary care. Making sense of a complex intervention: systematic review and meta-regression. *British Journal of Psychiatry*, 189, 484-493.
196. Kilminster, S.M. & Jolly, B.C. (2000). Effective supervision in clinical practice settings: a literature review. *Medical Education*, 34(10), 827-840.
197. Higgins, J.P.T. & Green, S. (2011). *Cochrane Handbook for Systematic Reviews of Interventions*. Chichester, UK: John Wiley & Sons Ltd.
198. Higgins, J.P.T., Thompson, S.G., Deeks, J.J. & Altman, D.G. (2003). Measuring inconsistency in meta-analyses. *British Medical Journal*, 327(7414), 557-560.
199. Sermeus, W. (2015). *Modelling process and outcomes in complex interventions*. *In:* Richards, D.A. & Hallberg, I. *Complex Interventions in Health: An Overview of Research Methods.* Oxton, UK: Routledge.
200. Hardeman, W., Sutton, S., Griffin, S., Johnston, M., White, A., Wareham, N.J. Kinmonth, A.L. (2005). A causal modelling approach to the development of theory-based behaviour change programmes for trial evaluation. *Health Education & Research*, 20(6), 676-687.
201. Ioannidis, J.P.A., Greenland, S., Hlatky, M.A., Khoury, M., Macleod, M.R., Moher, D., Schulz, K.F. & Tibshirani, R. (2014). Increasing value and reducing waste in research design, conduct, and analysis. *The Lancet*, 383(9912), 166-175.

202. Buhse, S. & Muhlhausser, I. (2015). Development of complex intervention: outcome modeling. *In:* Richards, D.A. & Hallberg, I. *Complex Interventions in Health: An Overview of Research Methods*. Oxton, UK: Routledge.
203. Rychetnik, L., Frommer, M., Hawe, P. & Shiell, A. (2002). Criteria for evaluating evidence on public health interventions. *Journal of Epidemiology & Community Health*, 56(2), 119-127.
204. NHS England (2016). *Implementing the five year forward view for mental health.*London, UK: The Independent Mental Health Taskforce.
205. British Medical Association (2015). *Prescribing in General Practice*.England: BMA.
206. Royal College of Nursing (2003). *Clinical supervision in the workplace: Guidance for occupational health nurses.* London, UK: Royal College of Nursing.
207. Edwards, D., Burnard, P., Hannigan, B., Cooper, L., Adams, J., Juggessur, T., Fothergil, A. & Coyle, D. (2006). Clinical supervision and burnout: the influence of clinical supervision for community mental health nurses. *Journal of Clinical Nursing*, 15(8), 1007-15.
208. Cochrane, D. (2011). *A best-practice case management model for patients with multi-morbidity*. London, UK: Cochrane Consulting.
209. Skills for Care & the Children's Workforce Development Council (2007). *Providing effective suoervision: A workforce development tool, including a unit of competence and supporting guidance.* London, UK: Skills for Care & the Children's Workforce Development Council.
210. Collington, V. & Browne, E. (2016). *Enhancing the preperation of mentors and supervisors in South London.* London, UK: Health Education England.
211. Moreo, K. & Lamb, G. (2003). CMSA updates standards of practice for case management. *Case Manager*, 14(3), 52-4.
212. Department of Health and NHS England (2014). *Framework agreement between Department of Health and NHS England.* London UK: Department of Health.
213. Alsop, A. (2013). Lifelong Learning and Continuing Professional Development. *In:* Alsop, A. *Continuing Professional Development in Health and Social Care*. Hoboken, USA: John Wiley & Sons Ltd.
214. Sonola, L., Thiel, V., Goodwin, N. & Kodner, D. (2013). *Oxleas Advanced Dementia Service: Supporting Carers and Building Resilience.* London, UK: The King's Fund.
215. The Health Foundation (2014). *Person-centred care made simple: what everyone should know about person-centred care*. London, UK: The Health Foundation.
216. Coalition for Collaborative Care Actions for Long-Term Conditions (2016). *Personalised care and support planning handbook: The journey to person-centred care*. London, UK: NHS England.
217. Public Health England (2014). *Multi-disciplinary teams in public health.* London, UK: Public Health England.
218. Better Care Fund Implemjentation Support Programme (2015). *How to work together across health, care and beyond*. London, UK: The Better Care Fund.
219. Department of Health (2009). *Living well with dementia: A national dementia strategy*. London, UK: Department of Health.
220. NICE (2011). *Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services.* [Accessed 06/2015]; Available from: https://www.nice.org.uk/guidance/cg136.
221. Ivbijaro, G.O., Enum, Y., Khan, A.A., Lam, S.S. & Gabzdyl, A. (2014). Collaborative Care: Models for Treatment of Patients with Complex Medical-Psychiatric Conditions. *Current Psychiatry Reports*, 16(11), 506.
222. Xyrichis, A. & Ream, E. (2008). Teamwork: a concept analysis. *Journal of Advanced Nursing*, 61(2), 232-41.
223. Nancarrow, S.A., Booth, A., Ariss, S., Smith, T., Enderby, P. & Roots, A. (2013). Ten principles of good interdisciplinary team work. *Human Resources for Health*, 11: 19.

224. Department of Health (2016). *Joint declaration on post-diagnostic dementia care and support.* London, UK: Department of Health.
225. The Health Foundation (2011). *Spotlight on dementia care: A health foundation improvement report*. London, UK: The Health Foundation.
226. Parliament of the United Kingdom (2008). *Health and Social Care Act*. [Accessed 06/2016]; Available from: https://www.legislation.gov.uk/ukpga/2008/14/pdfs/ukpga_20080014_en.pdf.
227. Ettema, R.G., Hoogendoorn, M.E., Kalkman, C.J. & Schuurmans, M.J. (2014). Development of a nursing intervention to prepare frail older patients for cardiac surgery (the PREDOCS programme), following phase one of the guidelines of the Medical Research Council. *European Journal of Cardiovascular Nursing*, 13(6), 494-505.
228. Tong, A., Sainsbury, P. & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349-357.
229. Given, L. (2008). Maximum Variation Sampling. *In:* Given, L. *The SAGE Encyclopaedia of Qualitative Research Methods*. Los Angeles, USA: SAGE Publications.
230. Kahn, P.V, Wishart, H.A., Randolph, J.S. & Santulli, R.B. (2016). Caregiver Stigma and Burden in Memory Disorders: An Evaluation of the Effects of Caregiver Type and Gender. *Current Gerontology and Geriatrics Research*, ID 8316045, 1-5.
231. Springate, B.A. & Tremont, G. (2014). Dimensions of Caregiver Burden in Dementia: Impact of Demographic, Mood, and Care Recipient Variables. *The American Journal of Geriatric Psychiatry*, 22(3), 294-300.
232. Pinquart, M. & Sörensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging*, 26(1), 1-14.
233. Guest, G., Bunce, A. & Johnson, L. (2006). How Many Interviews Are Enough?:An Experiment with Data Saturation and Variability. *Field Methods*, 18(1), 59-82.
234. Royal College of General Practitioners & Department of Health. *Dementia Roadmap: Helping primary care to support people with dementia*. [Accessed 10/2016]; Available from: https://dementiaroadmap.info/.
235. NIHR. *Join Dementia Research*. [Accessed 10/2016]; Available from: https://www.joindementiaresearch.nihr.ac.uk/.
236. Noy, C. (2008). Sampling Knowledge: The Hermeneutics of Snowball Sampling in Qualitative Research. *International Journal of Social Research Methodology*, 11(4), 327-344.
237. Srivastava, P. & Hopwood, N. (2009). A Practical Iterative Framework for Qualitative Data Analysis. *International Journal of Qualitative Methods*, 8(1), 76-84.
238. Department of Health (2007). *Mental Health Act*. London, UK: Department of Health.
239. Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C. & Suleman, R. (2014). Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expectations*, 17(5), 637-650.
240. Savage, C.L., Xu, Y., Lee, R., Rose, B.L., Kappesser, M. & Anthony, J.S. (2006). A Case Study in the Use of Community-Based Participatory Research in Public Health Nursing. *Public Health Nursing*, 23(5), 472-478.
241. Bird, C.M. (2005). How I Stopped Dreading and Learned to Love Transcription. *Qualitative Inquiry*, 11(2), 226-248.
242. Olson, J.D., McAllister, C., Grinnell, L.D., Walters, K.G. & Appunn, F. (2016). Applying constant comparative method with multiple investigators and inter-coder reliability. *The Qualitative Report*, 21(1), 26-42.
243. Bradbury-Jones, C. (2007). Enhancing rigour in qualitative health research: exploring subjectivity through Peshkin's I's. *Journal of Advanced Nursing*, 59(3), 290-8.
244. Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research*, 15(2), 219-234.

245. Martin, M. & McIntyre, L.C. (1994). *Readings in the Philosophy of Social Science*. Boston, USA: MIT Press.
246. Patton, M.Q. (1999). Enhancing the quality and credibility of qualitative analysis. *Health Services Research*, 34(5 Pt 2), 1189-1208.
247. Cornwell, J. (2012). *The care of frail older people with complex needs: time for a revolution*. London, UK: The King's Fund.
248. Thornicroft, G. (2006). *Actions speak louder ... tackling discrimination against people with mental illness*. London, UK: Mental Health Foundation.
249. Humphries, R., Hall, P., Charles, A., Thorlby, R. & Holder, H. (2016). *Social care for older people: Home truths*. London, UK: The King's Fund.
250. Jerofke, T.A. (2013). Concept analysis of empowerment from survivor and nurse perspectives within the context of cancer survivorship. *Research and Theory for Nursing Practice*, 27(3) 157-72.
251. The All Party Parliamentary Groups on Global Health; HIV/AIDs; Population, Development and Reproductive Health; Global Tuberculosis; and Patient and Public Involvement in Health and Social Care (2014). *Patient empowerment: for better quality, more sustainable health services globally*. London, UK: All Party Parliamentary Group.
252. Beck, C., Ortigara, A., Mercer, S. & Shue, V. (1999). Enabling and empowering certified nursing assistants for quality dementia care. *International Journal of Geriatric Psychiatry*, 14(3), 197-212.
253. Barbour, R.S. (2001). Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *BMJ*, 322(7294), 1115-1117.
254. Fusch, P.I. & Ness, L.R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, 20(9), 1408.
255. Malterud, K., Siersma, V.D. & Guassora, A.D. (2015). Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qualitative Health Research*, doi 1049732315617444.
256. Dowick, A. & Southern, A. (2014). *Dementia 2014: opportunity for change*. London, UK: Alzheimer's Society.
257. Moore, G.F., Bond, L., Hardeman, W., O'Cathain, A. & Wight, D. (2015). Process evaluation of complex interventions: Medical Research Council guidance. *BMJ*, 350.
258. Walker, E.M., Mwaria, M., Coppola, N. & Chen, C. (2014). Improving the Replication Success of Evidence-Based Interventions: Why a Preimplementation Phase Matters. *Journal of Adolescent Health*, 54(3, Supplement), S24-S28.
259. Boss, P. (2007). Ambiguous Loss Theory: Challenges for Scholars and Practitioners. *Family Relations*, 56(2), 105-111.
260. Lloyd, B.T. & Stirling, C. (2011). Ambiguous gain: uncertain benefits of service use for dementia carers. *Sociology of Health & Illness*, 33(6), 899-913.
261. Seidman, I. (2013). *Interviewing as Qualitative Research: A Guide for Researchers in Education and the Social Sciences*. New York, USA: Teachers College Press.
262. Kieffer, C.H. (1983). Citizen empowerment: a developmental perspective. *Prevention in Human Services*, 3(2-3), 9-36.
263. Adams, T. (1996). Kitwood's approach to dementia and dementia care: a critical but appreciative review. *Journal of Advanced Nursing*, 23(5), 948-953.
264. Goldsmith, M. (1996). *Hearing the Voice of People with Dementia: Opportunities and Obstacles*. London, UK: Jessica Kingley Publishers.
265. Elm, J.H.L., Lewis, J.P., Walters, K.L. & Self, J.M. (2016). “I'm in this world for a reason”: Resilience and recovery among American Indian and Alaska Native two-spirit women. *Journal of Lesbian Studies*, 20(3-4), 352-371.
266. Care Services Improvement Partnership (CSIP)(2007). *A common purpose: Recovery in future mental health services*. London, UK: Social Care Institute for Excellence.

267. Department of Health (2004). *Improving chronic disease management*. London, UK: Department of Health.
268. Case Management Society UK (2010). *What is case management.*[Accessed 06/2017]; Available from: https://www.cmsuk.org/case-management/what-is-case-management.
269. Gill, P., Stewart, K., Treasure, E. & Chadwick, B. (2008). Methods of data collection in qualitative research: interviews and focus groups. *British Dental Journal*, 204, 291.
270. NIHR (2017). *NIHR Research for Patient Benefit (RfPB) Programme Guidance on Applying for Feasibility Studies*. London, UK: NIHR.
271. Rossman, G.B. & Rallis, S.F. (2003). *Learning in the Field: An Introduction to Qualitative Research*. Thousand Oaks, USA: SAGE Publications.